DOCUMENT RESUME

ED 266 563 EC 181 726

TITLE A Guide to Selected National Genetic Voluntary Organizations.
INSTITUTION National Center for Education in Maternal and Child Health, Washington, DC.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE Nov 85
NOTE 137p.
PUB TYPE Reference Materials - Directories/Catalogs (132)

EDRS PRICE MF01/PC06 Plus Postage.
DESCRIPTORS *Congenital Impairments; *Genetics; Organizations (Groups); *Social Support Groups

ABSTRACT

The directory lists approximately 120 mutual support groups concerned with the medical and psychological impacts of genetic disorders and birth defects on individuals and their families. The groups are dedicated to serving the ongoing emotional, practical, and financial needs of these populations. The entries are arranged alphabetically and include information on name of organization, address, phone number, executive director, contact person, chapters/satellites, purpose, and educational materials (publications, audiovisuals, newsletters). Among conditions represented are acoustic neuroma, Alzheimer's disease, arthritis, autism, cerebral palsy, cystic fibrosis, Down's syndrome, epilepsy, Friedreich's ataxia, hemophilia, Huntington's disease, hydrocephalus, leukemia, lupus, multiple sclerosis, Parkinson's disease, Prader-Willi syndrome, scoliosis, spina bifida, and Tourette syndrome. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED266563

A Guide to Selected NATIONAL GENETIC VOLUNTARY ORGANIZATIONS

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

NCEMCH
National Center for Education in Maternal and Child Health
3520 Prospect Street, N.W.
Washington, D.C. 20057
202-625-8400

November 1985

EC181726

A Guide to Selected National Genetic Voluntary Organizations was produced and published by the National Center for Education in Maternal and Child Health, 3520 Prospect Street, N.W., Washington, D.C. 20057.

This bibliography is not copyrighted. Readers are free to duplicate and use all or part of the information contained therein. In accordance with accepted publication standards, the National Center requests acknowledgement, in print, of any information reproduced in another publication.

The National Center is a resource center that responds to public and professional inquiries in maternal and child health, including human genetics. Established in 1982, the NCEMCH provides services under a grant from the Division of Maternal and Child Health, Department of Health and Human Services.

Printed in the United States of America
88 87 86 85 5 4 3 2

Acoustic Neuroma Association (ANA) 2
Albinism and Hypopigmentation (NOAH), National Organization for 96
Alzheimer's Disease and Related Disorders Association, Inc. (ADRDA) 3
Amyotrophic Lateral Sclerosis (ALS) Foundation, Inc., The National 68
Arthritis Foundation 15
Arthrogryposis Multiplex Congenita (AVENUES), National Support Group for 101
Ataxia Foundation, National 74
Autism, National Society for Children and Adults with 100
Blind, Inc. (AFB), American Foundation for the 8
Brain Diseases Foundation for Research, The Children's 23
Brittle Bone Society (ABBS), American 4
Cancer Society, Inc., American 5
Caring, Inc. 20
Celiac Society, American 6
Celiac-Sprue Association (MCSA), Midwestern 64
Cerebral Palsy Associations, Inc. (UCPA), United 125
Charcot-Marie-Tooth (CMT) International 21
Cooley's Anemia Foundation, Inc. 25
Cornelia de Lange Syndrome (CdLS) Foundation, Inc. 26
Craniofacially Handicapped, National Association for the 69
Cystic Fibrosis (Mucoviscidosis) Association (I.C.F.(M).A.), International 51
Cystic Fibrosis (CF) Foundation 28
Cystinosis Foundation, Inc. 29
Deaf Children, American Society for 13
Deafness, National Information Center on 87
Diabetes Association, American 7
Diabetes Foundation International, Juvenile 56
Down Syndrome Congress, National 75
Down Syndrome Society, National 76
Down's Syndrome, Inc., Association for Children with 16
Dysautonomia Foundation, Inc., The 30
Dystonia Medical Research Foundation 31
Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (D.E.B.R.A.) 32
Easter Seal Society, National 77
Ectodermal Dysplasias (NFED), National Foundation for 78
Ehlers Danlos National Foundation 33
Epilepsy Foundation of America 34
Exceptional Children (CEC), The Council for 27
Exstrophy, National Support Group for 102
Facially Disfigured, Inc. (SFD), Society for the Rehabilitation of the 119
Fragile X Foundation, The 39
Fragile X Support Group, National 80
Freeman-Sheldon Parent Support Group 40
Friedreich's Ataxia Group in America, Inc. 41

Gaucher Foundation (NGF), National 81
Genetics Foundation, Inc., National 82
Gluten Intolerance Group of North America (GIG), The 42
Glycogen Storage Disease, Association for 17
Hemochromatosis Research Foundation, Inc., The 44
Hemophilia Foundation (NHF), The National 83
Hereditary Disease Foundation 45
Hereditary Hemorrhagic Telangiectasia Registry (HHTR) 46
Human Growth Foundation (HGF) 47
Huntington's Disease Association, Inc., National 84
Huntington's Disease Foundation of America, Inc. (HDFA), The 48
Hydrocephalus Foundation (NHF), The National 85
Hydrocephalus Parent Support Group 49
Hydrocephalus Research Foundation, Guardians of 43
Ichthyosis Foundation (NIF), The National 86
Immune Deficiency Foundation (IDF), The 50
Iron Overload Diseases Association, Inc. 55
Jewish Genetic Diseases, The National Foundation for 79
Joseph Diseases Foundation, Inc. (IJDF), International 53
Kidney Foundation, Inc., National 88
Laurence-Moon-Biedl Syndrome (LMBS) Support Network 57
Leukemia Society of America, Inc. 58
Leukodystrophy Foundation, Inc. (ULF), United 126
Little People of America, Inc. (LPA) 59
Liver Foundation, American 9
Liver Foundation, Inc., The Children's 24
Lowe's Syndrome Association 60
Lupus Erythematosus Foundation, Inc., National 89
Lupus Foundation of America, Inc., The 61
Lupus Society, The American 10
Lymphatic and Venous Diseases Association, National 90
Macular Diseases, Inc., Association for 18
Malignant Hyperthermia Association of the United States (MHAUS) 62
Maple Syrup Urine Disease, Families with 37
March of Dimes Birth Defects Foundation 63
Marfan Foundation, National 91
Mucolipidosis IV, The Children's Association for Research on 22
Mucopolysaccharidoses (MPS) Society, Inc., National 92
Multiple Sclerosis Society, National 93
Muscular Dystrophy Association (MDA) 65
Myasthenia Gravis Foundation, Inc. (MGF) 66
Myoclonus Families United 67
Myoclonus Foundation, National 94
Narcolepsy Association, American 11
Neurofibromatosis Foundation, Inc. (NF), The National 95
Neuro-Metabolic Disorders, Association for 19
Organic Acidemia Association, The 105
Osteogenesis Imperfecta Foundation, Inc. (OIF) 106
Paget's Disease Foundation, Inc. (PDF), The 107
Parents of Dwarfed Children 108
Parkinson Foundation (UPF), United 127
Parkinson's Disease Foundation 109
Polycystic Kidney Research (PKR) Foundation 110
Polyposis Registry, Familial 35
Porphyria Foundation, American 12

Prader-Willi Syndrome Association (PWSA) 111
Prescription Parents, Inc. 112
Progeria International Registry 113
Radiation Survivors (NARS), National Association of 73
Rare Disorders, Inc. (NORD), National Organization for 97
Rehabilitation International (RI) 114
Rehabilitation International USA (RIUSA) 115
RP Foundation Fighting Blindness 116
Rett's Syndrome Association (IRSA), International 54
Scleroderma Foundation, Inc. (USF), United 128
Scoliosis Association, Inc., The 117
Scoliosis Foundation, Inc., National 98
Sibling Information Network 118
Sickle Cell Clinics Foundation, Inc., National 99
Sickle Cell Disease, Inc. (NASCD), National Association for 71
Spina Bifida Association of America (SBAA) 120
Spinal Muscular Atrophy (S.M.A.), Families of 36
Tay-Sachs and Allied Diseases Association, Inc. (NTSAD), The National 103
Thrombocytopenia Absent Radius Syndrome Association (TARSA) 122
Tourette Syndrome Association, Inc. (TSA) 123
Trisomy 18/13 (SOFT), Support Organization for 121
Tuberous Sclerosis Association, Inc. (ATSA), American 14
Tuberous Sclerosis Association, Inc. (NTSA), National 104
Turner's Syndrome Society 124
Visually Handicapped, National Association for 72
Visually Impaired, Inc. (NAPVI), The National Association for Parents of the 70
Visually Impaired, 0-7, Inc., International Institute for 52
Williams Syndrome Association 129
Wilson's Disease Association 130
Wilson's Disease, Inc., Foundation for the Study of 38
Xeroderma Pigmentosum Registry 131

FOREWORD

A Guide to Selected National Genetic Voluntary Organizations is a directory of mutual support groups concerned with the medical and psychosocial impacts of genetic disorders and birth defects on affected individuals and families. Each of the support groups listed in this directory is dedicated to serving the ongoing emotional, practical, and financial needs of these populations. Through shared experience and understanding, these groups offer services and guidance crucial to the effective management of often frustrating and isolating situations.

By presenting synopses of these groups, we hope to further public awareness of their existence and their representative disorders. All information has been obtained from an organizational spokesperson, either through mail questionnaires or telephone inquiries. The entries are arranged alphabetically, while the user's guide is organized according to each group's advocated disorder.

The efforts of each organization are greatly appreciated. We regret any inadvertent omissions. Notification of changes, additions, or deletions should be sent to Genetics Associate, The National Center for Education in Maternal and Child Health, 3520 Prospect St., N.W., Washington, D.C. 20057.

Debra B. Lezama
Project Coordinator
Washington, DC
October, 1985

Name of Organization : **Acoustic Neuroma Association (ANA)**

Address : P.O. Box 398

Carlisle, PA 17013

Phone No. : (717) 249-3973

Executive Director : Virginia Fickel, President

Contact Person : Virginia Fickel, President

Chapters/Satellites : Canada and Australia

Statement of Purpose :

The Acoustic Neuroma Association is a patient-organized support and information organization for those who face or have undergone acoustic neuroma removal. Founded in 1981, the Association offers understanding and assistance to those experiencing cranial nerve deficits. It also promotes and supports education and research on the cause, development, and treatment of acoustic neuromas and other benign cranial tumors.

Educational Materials:

Publication(s) : Acoustic Neuroma

Audiovisual(s) : None

Newsletter(s) : Notes (Quarterly)

Name of Organization : Alzheimer's Disease and Related Disorders Association, Inc. (ADRDA)

Address : 360 North Michigan Avenue
Chicago, IL 60601

Phone No. : (312) 853-3060

Executive Director : Thomas M. Ennis

Contact Person : Thomas M. Ennis

Chapters/Satellites : 125 throughout the United States

Statement of Purpose :

The Association was established in 1980 as a coalition of lay persons working to contain and conquer Alzheimer's disease. Its program goals are directed toward enhancing public awareness of this debilitating condition and impacting public policy. The Association responds to information requests, referring those requiring further assistance to local organizations.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : ADRDA Newsletter (Quarterly)

Name of Organization : American Brittle Bone Society (ABBS)

Address : 1256 Merrill Drive, Marshallton

West Chester, PA 19380

Phone No. : (215) 692-6248

Executive Director : Roberta DeVito

Contact Person : Roberta DeVito

Chapters/Satellites : None

Statement of Purpose :

The American Brittle Bone Society, established in 1977 by parents and professionals, promotes research and provides information on the brittle bone diseases, osteogenesis imperfecta, and osteoporosis. The Society sponsors seminars nationwide, provides brochures and technical publications to the interested public and health professionals, and prompts research-funding organizations to increase their support for brittle bone disease research. In the future, it hopes to fund research into these diseases.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Brittle Bones

Newsletter(s) : On the Record (Periodically)

Name of Organization : American Cancer Society, Inc.

Address : 4 West 35th Street

New York, NY 10001

Phone No. : (212) 736-3030

Executive Director : Lane W. Adams, Executive Vice President

Contact Person : Susan Hernandez, Public Information

Chapters/Satellites : 3,000+ local units under 58 divisions

Statement of Purpose :

The American Cancer Society's long-range objective is to eliminate cancer as a human disease. The immediate goal is to save more lives and to diminish suffering from cancer. The Society provides educational materials and information for the patient, family, and professional.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Cancer News (Triannually)

Name of Organization : American Celiac Society

Address : 45 Gifford Avenue

Jersey City, NJ 07304

Phone No. : (201) 432-1207

Executive Director : Anita Garrow

Contact Person : Anita Garrow

Chapters/Satellites : None

Statement of Purpose :

The American Celiac Society provides education and information materials on gluten-free diets to patients, physicians, nutritionists, and others. The Society responds to information and provides referral to a gluten intolerance group.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : None

Name of Organization : American Diabetes Association

Address : 2 Park Avenue

New York, NY 10016

Phone No. : (212) 683-7444

Executive Director : Robert S. Bolan

Contact Person : Robert S. Bolan

Chapters/Satellites : 59 affiliates; 700 chapters in all 50 states and the District of Columbia

Statement of Purpose :

The American Diabetes Association focuses on both the present and future needs of the U.S. diabetes population through its twofold mission: (1) to promote the search for a cure for diabetes; and (2) to improve the well-being of all people with diabetes and their families. It offers camps, support groups, and workshops to adults and children with diabetes and their families; workshops, symposia, and materials to professionals; and awareness and detection programs to the general public.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Diabetes - The Journey and the Dream
The Other Diabetes
No Sugar Coating

Newsletter(s) : Diabetes '85 (Quarterly)
Clinical Diabetes (Bimonthly)

Name of Organization : **American Foundation for the Blind, Inc. (AFB)**

Address : 15 West 16th Street

New York, NY 10011

Phone No. : (212) 620-2000

Executive Director : William F. Gallagher

Contact Person : Corinne Kirchner, Director of Social Research

Chapters/Satellites : 5: DC; IL; GA; TX; CA

Statement of Purpose :

The Foundation provides information and referral in the areas of education, social services, and rehabilitation for blind or severely visually impaired individuals.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : AFB News (Quarterly)

Name of Organization : American Liver Foundation

Address : 998 Pompton Avenue

Cedar Grove, NJ 07009

Phone No. : (201) 857-2626 (800) 223-0179

Executive Director : Thelma King Thiel, President and Chief Operating Officer

Contact Person : Thelma King Thiel, President and Chief Operating Officer

Chapters/Satellites : 27 throughout the United States

Statement of Purpose :

The American Liver Foundation is dedicated to reducing the human suffering, social and economic burdens, and loss of life caused by diseases of the liver, gall bladder, and bile ducts. The Foundation works toward its goals by soliciting, administering, and disbursing funds to: (1) increase public understanding of the diseases and of available therapy and prevention methods; (2) improve diagnosis and treatment; (3) sponsor support groups for victims of liver disease and their families; and (4) promote scientific investigation into the causes, prevention, and treatment of these diseases.

Educational Materials:

Publication(s) : Biliary Atresia
Cirrhosis - Many Causes
Diet and Your Liver
Liver Disease - A Problem for the Child?
Seeking Solutions
Viral Hepatitis - Everybody's Problem?
Your Liver Lets You Live

Audiovisual(s) : The Liver and Its Diseases: The Knowledge Crisis

Newsletter(s) : Progress (Quarterly)
Sharing Cares and Hopes (Periodically)

Name of Organization : The American Lupus Society

Address : 23751 Madison Street

Torrance, CA 90505

Phone No. : (213) 373-1335

Executive Director : Frederic B. Clark, Jr.

Contact Person : Charlean Wakefield

Chapters/Satellites : 27 throughout the United States

Statement of Purpose :

The Society engages in programs aimed to increase public awareness about lupus and obtains funds for research. Patients and their families are provided with educational materials and support.

Educational Materials:

Publication(s) : Lupus Erythematosus (booklet)
Lupus Erythematosus (foldout)
The Butterfly Mask
Lupus bookmarks

Audiovisual(s) : None

Newsletter(s) : The Quarterly

Name of Organization : American Narcolepsy Association

Address : P.O. Box 5846

Stanford, CA 94305

Phone No. : (415) 591-7979

Executive Director : William P. Baird

Contact Person : Jolie A. Bou

Chapters/Satellites : None

Statement of Purpose :

The American Narcolepsy Association attempts to solve the medical and psychosocial problems associated with narcolepsy and related sleep disorders through public education, research promotion, and medical and professional education. Referral services to physicians and sleep centers are offered to persons with sleep disorders.

Educational Materials:

Publication(s) : Narcolepsy: A Non-Technical Presentation
Narcolepsy: A Non-Technical Summary
Narcolepsy: Care and Treatment - A Guide for the Primary Care Physician
Sleep Apnea: A Non-Technical Presentation
Keep Us Awake: A Film Guide

Audiovisual(s) : Keep Us Awake

Newsletter(s) : Eye Opener (Quarterly)

Name of Organization : American Porphyria Foundation

Address : P.O. Box 11163

Montgomery, AL 36111

Phone No. : (205) 264-2564

Executive Director : Desiree Dodson

Contact Person : Desiree Dodson

Chapters/Satellites : 18 support groups

Statement of Purpose :

The American Porphyria Foundation was established in 1982 to increase public/physician knowledge, awareness, and support of the porphyrias; to locate patients and establish support networks; and to provide financial support for research into this group of rare blood disorders.

Educational Materials:

Publication(s) : Questions Commonly Asked
The Porphyrias
Acute Intermittent Porphyria
Safe Drug List For AIP

Audiovisual(s) : The Porphyrias
LHRH Treatment For AIP (Rockefeller University)

Newsletter(s) : (Quarterly)

Name of Organization : American Society for Deaf Children

Address : 814 Thayer Avenue

Silver Spring, MD 20910

Phone No. : (301) 585-5400 (Voice and TDD)

Executive Director : Jacqueline Z. Mendelsohn

Contact Person : Millie Maisel

Chapters/Satellites : 96 throughout the United States

Statement of Purpose :

The American Society for Deaf Children provides information and support to parents and families with deaf or hearing impaired children. Services are also available to the general public. The Society offers assistance with educational or legal problems related to the rearing of a hearing impaired child.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : The Endeavor (Bimonthly)

Name of Organization : American Tuberous Sclerosis Association, Inc. (ATSA)

Address : P.O. Box 44
Rockland, MA 02370

Phone No. : (617) 878-5528 (800) 446-1211

Executive Director : Shirley L. Cort

Contact Person : Raymond A. Connors

Chapters/Satellites : Representatives throughout the country

Statement of Purpose :

ATSA is dedicated to supporting and stimulating research on tuberous sclerosis, as well as public and professional education. It also serves as a contact service for patients, families, and health professionals.

Educational Materials:

Publication(s) : ATSA Picture Brochure
A Brief Description of Tuberous Sclerosis

Audiovisual(s) : None

Newsletter(s) : A.T.S.A. (Biannually)

Name of Organization : **Arthritis Foundation**

Address : 1314 Spring Street, NW

Atlanta, GA 30309

Phone No. : (404) 872-7100

Executive Director : Clifford Clarke, President

Contact Person : Clifford Clarke, President

Chapters/Satellites : Chapters and divisions in 50 states and metropolitan areas.

Statement of Purpose :

The Arthritis Foundation is concerned with issues surrounding this debilitating condition, and offers educational programs and informative literature.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : (Several at various intervals)

Name of Organization : Association for Children with Down's Syndrome, Inc.

Address : 2616 Martin Avenue

Bellmore, New York 11710

Phone No. : (516) 221-4700

Executive Director : Fredda Stimell

Contact Person : Emily Lewis

Chapters/Satellites : None

Statement of Purpose :

The Association for Children with Down's Syndrome is a parent-founded organization and school whose basic premise holds that early intervention in Down syndrome can make a significant difference in each child's ability to become a functioning member of society. It offers services through many channels, including a school program for children from birth to five years, professional referrals, a volunteer program, and research support. Through peer counseling, meetings, and advocacy, parents are provided with emotional and educational support.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Spotlite on Down's Syndrome (Five issues/year)

Name of Organization : **Association for Glycogen Storage Disease**

Address : Box 896

Durant, IA 52747

Phone No. : (319) 785-6038

Executive Director : Hollie L. Arp

Contact Person : Hollie L. Arp

Chapters/Satellites : None

Statement of Purpose :

The Association was founded in 1979 to introduce individuals with glycogen storage disease and their families to current medical information and to each other.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : The Ray (Quarterly)

Name of Organization : **Association for Macular Diseases, Inc.**

Address : 210 East 64th Street

New York, NY 10021

Phone No. : (212) 605-3719

Executive Director : Nicholai Stevenson

Contact Person : Janet DeRosa

Chapters/Satellites : None

Statement of Purpose :

The Association acts as a support group for individuals and their families adjusting to the restrictions and changes brought about by macular disease. It services its members through a newsletter containing current information on medical advances and developments in low-vision aids. A forum for emotional support and counseling is provided for affected persons. It is the only organization solely concerned with the entire macular disease spectrum.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : **Association for Neuro-Metabolic Disorders**

Address : 5223 Brookfield Lane

Sylvania, OH 43560

Phone No. : (419) 885-1497

Executive Director : None

Contact Person : Cheryl Volk

Chapters/Satellites : None

Statement of Purpose :

The Association serves those affected with medical conditions caused by disturbances in body chemistry. These conditions are present at birth and affect brain function. Since these disorders require prompt recognition and care, the Association is dedicated to promoting education and research in order to increase awareness. Support and informational resources are offered to affected individuals and other interested parties.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : (Triannually)

Name of Organization : Caring, Inc.

Address : P.O. Box 400

Milton, WA 98354

Phone No. : (206) 922-8194

Executive Director : Sharon Shimizu

Contact Person : Tina Tossey

Chapters/Satellites : None

Statement of Purpose :

Founded by parents and professionals interested in the health and welfare of persons with Down syndrome, Caring provides various support materials for parents and professionals, and an early intervention manual for parents, students, and educators.

Educational Materials:

Publication(s) : DS Directory
Down's Syndrome Resource List

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Sharing Our Caring (Five issues/year)

Name of Organization : **Charcot-Marie-Tooth (CMT) International**

Address : 34-B Bayview Drive

St. Catharines, Ontario CANADA L2N 4Y6

Phone No. : (416) 937-3851

Executive Director : Linda Crabtree

Contact Person : Linda Crabtree

Chapters/Satellites : None

Statement of Purpose :

CMT International helps those with Charcot-Marie-Tooth syndrome, also known as peroneal muscular atrophy, to better cope with the disease through information, source finding, and psychological and genetic counseling. CMT International also provides a registry for researchers, enabling them to locate individuals for analyses.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : CMT Newsletter (Quarterly)

Name of Organization : **The Children's Association for Research on Mucolipidosis IV**

Address : 6 Concord Drive
Moncey, NY 10952

Phone No. : (914) 425-0639

Executive Director : Lynn Goldblat

Contact Person : Lynn Goldblat

Chapters/Satellites : None

Statement of Purpose :

The Association unites parents and professionals and provides information and support to parents of affected children. In addition, the Association works to raise funds to support research into mucolipidosis IV.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : The Children's Brain Diseases Foundation for Research

Address : 350 Parnassus, Suite 900
San Francisco, CA 94117

Phone No. : (415) 566-5402

Executive Director : J. Alfred Rider, M.D.

Contact Person : J. Alfred Rider, M.D.

Chapters/Satellites : None

Statement of Purpose :

The Children's Brain Diseases Foundation for Research raises funds for research into Batten disease and other childhood brain diseases and refers families of affected persons to researchers.

Educational Materials:

Publication(s) : Batten's Disease (brochure)

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : The Children's Liver Foundation, Inc.

Address : 155 Maplewood Avenue

Maplewood, NJ 07040

Phone No. : (201) 761-1111

Executive Director : Maxine Turon, President

Contact Person : Maxine Turon, President

Chapters/Satellites : 22 throughout the United States

Statement of Purpose :

The Children's Liver Foundation organizes and funds liver research, and provides support services to families. In addition to these functions, it is also working to establish an information network to further educate professionals and the general public about liver disorders.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Lifeline (Quarterly)

Name of Organization : **Cooley's Anemia Foundation, Inc.**

Address : 105 East 22nd Street, Suite 911

New York, NY 10010

Phone No. : (212) 598-0911 (800) 221-3571 (nationally)

(800) 522-7222 (within New York)

Executive Director : Michael C. DiFilippo

Contact Person : Michael C. DiFilippo

Chapters/Satellites : 13: FL; NY (8); NJ; IL; PA; CA

Statement of Purpose :

The Cooley's Anemia Foundation provides patient care and family support services by supplying batteries, pumps, and Desferal to patients in need. The Foundation educates and counsels the public, establishes professional education programs, and provides research grants and fellowships.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Lifeline (Quarterly)

Name of Organization : Cornelia de Lange Syndrome (CdLS) Foundation, Inc.

Address : 60 Dyer Avenue

Collinsville, CT 06022

Phone No. : (203) 693-0159

Executive Director : Julie A. Mairano

Contact Person : Julie A. Mairano

Chapters/Satellites : None

Statement of Purpose :

The Foundation supports parents and children affected by Cornelia de Lange syndrome. It increases public awareness through the collection and dissemination of information regarding the syndrome's various aspects, and funds research into the disorder.

Educational Materials:

Publication(s) : Cornelia de Lange Syndrome: A Book for Families
Facts about Cornelia de Lange Syndrome
CdLS Directory

Audiovisual(s) : None

Newsletter(s) : Reaching Out (Bimonthly)

Name of Organization : The Council for Exceptional Children (CEC)

Address : 1920 Association Drive

Reston, VA 22091

Phone No. : (703) 620-3660

Executive Director : Jeptha V. Greer

Contact Person : Jeptha V. Greer

Chapters/Satellites : State level federations and chapters; 13 national divisions

Statement of Purpose :

The Council attempts to advance the education of exceptional children and youth of the United States and Canada, whether gifted, retarded, impaired, or disabled.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Exceptional Children (Six issues/year)
Teaching Exceptional Children (Quarterly)

Name of Organization : **Cystic Fibrosis (CF) Foundation**

Address : 6000 Executive Boulevard, Suite 510

Rockville, MD 20852

Phone No. : (301) 881-9130

Executive Director : Robert Dresing, President

Contact Person : Robert J. Beall, Ph.D., Executive Vice President Medical Affairs

Chapters/Satellites : 65 chapters; 126 care centers located throughout the United States

Statement of Purpose :

The Cystic Fibrosis Foundation attempts to develop a means to control, cure, and prevent cystic fibrosis. The Foundation strives to improve the quality of life for those affected by the disease. It also supports biomedical research and provides accreditation and support of specialized care centers for CF patients throughout the United States.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Commitment (Quarterly)

Name of Organization : Cystinosis Foundation, Inc.

Address : 477 15th Street, Suite 200

Oakland, CA 94612

Phone No. : (415) 834-7897

Executive Director : None

Contact Person : Jean Hotz, President

Chapters/Satellites : Now being formed

Statement of Purpose :

The Foundation works to (1) act as a support group for parents; (2) raise the awareness of the general public and medical community; (3) raise funds for research.

Educational Materials:

Publication(s) : What is Cystinosis?
How is the Kidney Affected in Cystinosis?
Rickets and the Kidneys
Food Suggestions from Parents
Stress on the Family (in progress)

Audiovisual(s) : None

Newsletter(s) : Help Us Grow (Quarterly)

Name of Organization : The Dysautonomia Foundation, Inc.

Address : 370 Lexington Avenue, Room 1504

New York, NY 10017

Phone No. : (212) 889-5222

Executive Director : Lenore F. Roseman

Contact Person : Lenore F. Roseman

Chapters/Satellites : 14: CA; IL; MA (2); NJ; MD; MI; PA; FL; NY; CT; Canada (2); Great Britain

Statement of Purpose :

The Dysautonomia Foundation, founded in 1951, provides a continual flow of information to parents, physicians, and professionals. Through its fund-raising efforts and the assistance of its fourteen chapters located in cities across the United States, Canada, and Great Britain, it maintains and supports the Dysautonomia Treatment and Evaluation Center at New York University Medical Center; these monies enable patients to undergo evaluations and have access to a 24-hour answering service free of charge.

Educational Materials:

Publication(s) : Caring for the Child with Familial Dysautonomia (A Treatment Manual) by Felicia B. Axelrod, M.D.
Familial Dysautonomia: A Nursing Care Plan by Arlene P. Osoff, R.N.

Audiovisual(s) : None

Newsletter(s) : DYS/COURSE (Biannually)

Name of Organization : Dystonia Medical Research Foundation

Address : 9615 Brighton Way, Suite 310

Beverly Hills, CA 90210

Phone No. : (213) 272-9880

Executive Director : Lois Raphael (Canadian Office)

Contact Person : Nancy Harris (U.S. Office)

Chapters/Satellites : 7: IL; NY; Delaware Valley; New England; CA; MO; Montreal, Canada

Statement of Purpose :

The Dystonia Medical Research Foundation strives to increase awareness of dystonia and related disorders through the collection and dissemination of current data on these conditions. The Foundation serves patients and their families by providing information, and assists researchers and qualified scientists by offering research monies.

Educational Materials:

Publication(s) : Fact Sheet: Torsion Dystonia

Audiovisual(s) : Dystonia

Newsletter(s) : (Quarterly)

Name of Organization : Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (D.E.B.R.A.)

Address : Kings County Medical Center
451 Clarkson Avenue Bldg. E, 6th Floor, Room E6101
Brooklyn, NY 11203

Phone No. : (718) 774-8700

Executive Director : Arlene Pessar, R.N.

Contact Person : Arlene Pessar, R.N.

Chapters/Satellites : Regional support groups

Statement of Purpose :

D.E.B.R.A. promotes and supports basic and clinical research in epidermolysis bullosa (EB); provides information for patients, families, health professionals, and the general public; distributes educational material on EB; and assists in finding medical care, social services, and genetic counseling for those in need.

Educational Materials:

Publication(s) : Impossible Victory of Eric Lopez
Hope Through Research
Facts About D.E.B.R.A.
Thin-Skinned Kids
Living with Epidermolysis Bullosa

Audiovisual(s) : None

Newsletter(s) : E.B. Currents (Quarterly)

Name of Organization : **Ehlers Danlos National Foundation**

Address : P.O. Box 1212

Southgate, MI 48195

Phone No. : (313) 282-0180

Executive Director : Nancy A. Hanna

Contact Person : Nancy A. Hanna

Chapters/Satellites : None

Statement of Purpose :

The Foundation was founded in mid-1985 with the primary purpose of providing support to those suffering from any type of Ehlers Danlos syndrome (EDS), and their families. The Foundation hopes to become a national information, referral, and resource center by collecting family history records, recording successful therapy techniques, and maintaining literature and listings of physicians, geneticists, and medical institutions with a basic understanding of EDS.

Educational Materials:

Publication(s) : In progress

Audiovisual(s) : None

Newsletter(s) : In progress

Name of Organization : Epilepsy Foundation of America

Address : 4351 Garden City Drive

Landover, MD 20785

Phone No. : (301) 459-3700

Executive Director : William M. McLin

Contact Person : Ann Scherer, Director of Information and Education

Chapters/Satellites : 81 independently chartered organizations are affiliated with the Foundation

Statement of Purpose :

The Foundation attempts to prevent epilepsy, improve its treatment, and enhance the welfare of affected individuals and their families. These goals are addressed through a variety of national and local programs of research, education, advocacy, and direct services.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : National Spokesman (Ten issues/year)
Capital Observer (Available upon request)

Name of Organization : **Familial Polyposis Registry**

Address : Department of Colorectal Surgery
Cleveland Clinic Foundation
9500 Euclid Avenue
Cleveland, OH 44106

Phone No. : (216) 444-6470

Executive Director : David Jagelman, M.D.

Contact Person : Ellen McGannon

Chapters/Satellites : Network of registries in NY (2); MD; NE; WV; TX, UT; Toronto, Canada

Statement of Purpose :

The Registry aims to identify and treat patients with familial polyposis. It is also concerned with educating these individuals and their kindred, as well as the medical profession, about this disease. The genetic influence of polyposis for large bowel cancer is also being explored.

Educational Materials:

Publication(s) : None

Audiovisual(s) : Slides for lecture presentations

Newsletter(s) : G.I. Polyposis and Related Conditions
(Joint newsletter with Johns Hopkins Hospital, Baltimore, MD)

Name of Organization : Families of S.M.A. (Spinal Muscular Atrophy)

Address : P.O. Box 1465

Highland Park, IL 60035

Phone No. : (312) 432-5551

Executive Director : Audrey N. Lewis

Contact Person : Audrey N. Lewis

Chapters/Satellites : 4: OH, CA, CO, IN

Statement of Purpose :

Families of S.M.A. raises funds for research, provides patient support and promotes public awareness of Werdnig-Hoffmann disease, Kugelberg-Welander disease, benign congenital hypotonia, and Aran-Duchenne disease.

Educational Materials:

Publication(s) : Various booklets on treatment and coping strategies

Audiovisual(s) : Videocassettes and a slide presentation

Newsletter(s) : (Quarterly)

Name of Organization : **Families with Maple Syrup Urine Disease**

Address : 24806 SR 119

Goshen, IN 46526

Phone No. : (219) 862-2922

Executive Director : Joyce Brubacher, Editor

Contact Person : Joyce Brubacher, Editor

Chapters/Satellites : None

Statement of Purpose :

This organization provides emotional support to families having children with maple syrup urine disease (MSUD). A newsletter provides information on diets and profiles of families coping with the disorder.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : M.S.U.D. Newsletter (Triannually)

Name of Organization : **Foundation for the Study of Wilson's Disease, Inc.**

Address : 5447 Palisade Avenue

Bronx, NY 10471

Phone No. : (212) 430-2091

Executive Director : I. Herbert Scheinberg, M.D., President

Contact Person : Irmin Sternlieb, M.D., Vice President

Chapters/Satellites : None

Statement of Purpose :

The Foundation provides clinical and laboratory facilities for the diagnosis and management of Wilson disease and related disorders of copper and metal metabolism. In addition, it educates health professionals and the lay public to recognize undiagnosed patients with Wilson disease - symptomatic or asymptomatic - and appropriately manages these patients with effective decoppering therapy.

Educational Materials:

Publication(s) : Wilson's Disease

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : The Fragile X Foundation

Address : P.O. Box 300233

Denver, CO 80203

Phone No. : (303) 861-6630

Executive Director : Alfred W. (Tad) Jackson, III

Contact Person : Alfred W. (Tad) Jackson, III

Chapters/Satellites : 4: CA; CO; IL; NY

Statement of Purpose :

The Fragile X Foundation educates professionals, parents, and the public regarding diagnosis and treatment of the Fragile X syndrome and other forms of X-linked mental retardation. The Foundation promotes research pertaining to X-linked mental retardation in the areas of biochemistry, genetics, and clinical applications. The Foundation also pursues active involvement in the organization of parent support groups across the country.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : In progress

Name of Organization : Freeman-Sheldon Parent Support Group

Address : 1459 East Maple Hills Drive

Bountiful, UT 84010

Phone No. : (801) 298-3149

Executive Director : Joyce Dolcourt

Contact Person : Joyce Dolcourt

Chapters/Satellites : None

Statement of Purpose :

This organization provides emotional support for parents and disseminates medical information.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : Friedreich's Ataxia Group in America, Inc.

Address : P.O. Box 11116

Oakland, CA 94611

Phone No. : (415) 658-7014

Executive Director : Raymond S. McCarthy

Contact Person : Myrna J. Lesinsky, Administrative Assistant

Chapters/Satellites : 23: IL; KY; LA; MT; IN; TX; MD/DC; FL; AZ; OR; AL; NY/VT; CT; KS; MA; NC; OH; PA/NJ/DE; RI; SC; TN; WA; WI

Statement of Purpose :

Friedreich's Ataxia Group in America, established in 1969, is primarily committed to three goals: (1) benefiting persons with Friedreich's ataxia and their families, especially through chapters and the newsletter; (2) fundraising for research, and (3) educating affected individuals, physicians, and the general public. Contributions are applied directly to research and to administrative expenses.

Educational Materials:

Publication(s) : Fact Sheet

Audiovisual(s) : None

Newsletter(s) : (Two to four issues/year)

Name of Organization : The Gluten Intolerance Group of North America (GIG)

Address : P.O. Box 23053

Seattle, WA 98102

Phone No. : (206) 325-6980 (206) 854-9606

Executive Director : Elaine I. Hartsook

Contact Person : Elaine I. Hartsook

Chapters/Satellites : 25: AK; CA (4); FL; IL; MN; MO; MT (2); NC; OH (2); OR (2); PA; SC; UT; WA (5); DC/VA

Statement of Purpose :

The Gluten Intolerance Group offers assistance and information to persons with celiac-sprue, their families, and health professionals through publications, seminars, and by funding research. The Group also collaborates closely with other digestive disease organizations.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : GIG Newsletter (Quarterly)

Name of Organization : Guardians of Hydrocephalus Research Foundation

Address : 2618 Avenue Z

Brooklyn, NY 11235

Phone No. : (718) 743-GHRF

Executive Director : Michael Fischette

Contact Person : Katherine Soriano

Chapters/Satellites : Chapters: NY (2), NJ (1)
Satellites: NY, CA (2), VA, LA, AR

Statement of Purpose :

The Foundation raises funds for research into the causes, prevention, control and/or cure of hydrocephalus. By disseminating information, the Foundation works to develop a better understanding of hydrocephalus among patient's families and the general public. A 24-hour hot-line and a referral and information center are provided.

Educational Materials:

Publication(s) : What is Hydrocephalus?
For the Parents of Children with Hydrocephalus

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : The Hemochromatosis Research Foundation, Inc.

Address : P.O. Box 8569

Albany, NY 12208

Phone No. : (518) 489-0972

Executive Director : Margaret A. Krikker, M.D.

Contact Person : Margaret A. Krikker, M.D.

Chapters/Satellites : Now being formed

Statement of Purpose :

Hereditary hemochromatosis is now known to be one of the most common genetic disorders but is rarely diagnosed before clinically manifest or before death. The organ damage that results from the disease is reversible and preventable with early diagnosis and treatment. The major goals of the Hemochromatosis Research Foundation include: (1) to increase public and medical community awareness of the disorder; (2) to identify families with the disorder through screening; (3) to continue joint screening program with American Red Cross throughout the nation; and (4) to solicit funds for screening and research. Patients are offered educational materials, counseling, and physician referrals.

Educational Materials:

Publication(s) : Some Facts About . . . Hemochromatosis
Hereditary (Genetic or Idiopathic) Hemochromatosis

Audiovisual(s) : None

Newsletter(s) : Hemochromatosis Awareness (Quarterly)

Name of Organization : **Hereditary Disease Foundation**

Address : 606 Wilshire Boulevard, Suite 504

Santa Monica, CA 90401

Phone No. : (213) 458-4183

Executive Director : Allan J. Tobin, Executive Director, Science Board

Contact Person : Jodie Evans, Administrative Director

Chapters/Satellites : None

Statement of Purpose :

The Foundation conducts basic biomedical research in hereditary disease with a focus on such genetic disorders as Huntington disease and other neurological illnesses. These activities are accomplished through grant programs, workshops, postdoctorate fellowship programs, and support of biological specimen banks at Harvard University and UCLA.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : In progress

Name of Organization : Hereditary Hemorrhagic Telangiectasia Registry (HHTR)
(Osler-Weber-Rendu syndrome)

Address : RFD 3 - Pratt Corner
Amherst, MA 01002

Phone No. : (413) 256-6071 (413) 545-2048

Executive Director : Linda Jacobson

Contact Person : Linda Jacobson

Chapters/Satellites : None

Statement of Purpose :

Founded in early 1985, HHTR is concerned with offering support to affected individuals and promoting research into the syndrome's cause and cure. These are accomplished by: (1) helping to identify at-risk family members; (2) informing patients and physicians about new forms of treatment and progress in research; (3) gathering epidemiological data; (4) providing a pool of individuals interested in participating in clinical or statistical analyses; and (5) providing a network of support.

Educational Materials:

Publication(s) : In progress

Audiovisual(s) : None

Newsletter(s) : In progress

Name of Organization : **Human Growth Foundation (HGF)**

Address : 4720 Montgomery Lane, Suite 909

Bethesda, MD 20814

Phone No. : (301) 656-6904 (301) 656-7540

Executive Director : Denise Orenstein

Contact Person : Denise Orenstein

Chapters/Satellites : 12 nationwide

Statement of Purpose :

The Human Growth Foundation was created in 1965 by a group of parents whose children had severe growth problems. Since that time, HGF has expanded to over 800 members (including health professionals) and administers an annual research program aimed at providing investigators with the financial resources to study issues in growth and its deviations. It also provides information to physicians and the community-at-large.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : (Monthly)

Name of Organization : The Huntington's Disease Foundation of America, Inc. (HDFA)

Address : 250 West 57th Street, Suite 2016
New York, NY 10107

Phone No. : (212) 757-0443

Executive Director : Gary Wallach

Contact Person : Mina Kyung Chang

Chapters/Satellites : 42 chapters, affiliates and branches, and another 70-plus area representatives and medical advisors in major urban centers and smaller communities throughout the United States of America.

Statement of Purpose :

The Foundation is the world's oldest and largest national organization dedicated to the care of Huntington disease patients and their families, and to the search for treatment and cure for HD. Its information and referral services tap a nationwide network of physicians, scientists, social workers, and other relevant professionals. In addition, the Foundation provides fellowship grants and seed money to qualified research scientists, and supports and coordinates a Brain Donor program which enlists the help of HD families in donating tissue essential to scientific research.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : The Marker (Triannually)

Name of Organization : Hydrocephalus Parent Support Group

Address : 225 Dickinson Street, H-893

San Diego, CA 92103

Phone No. : (619) 695-3139 (619) 726-0507

Executive Director : Jackie Cotten, R.N.

Contact Person : Jackie Cotten, Lynn Frank

Chapters/Satellites : None

Statement of Purpose :

This organization strives to increase awareness of the medical, legal and educational issues that families face when a child is affected with hydrocephalus, spina bifida or a related condition. Social interaction between families is encouraged.

Educational Materials:

Publication(s) : Material for parents on hydrocephalus, spina bifida, myelomeningocele, CAT scans, brain tumors, and head injury.

Audiovisual(s) : None

Newsletter(s) : (Bimonthly)

Name of Organization : The Immune Deficiency Foundation (IDF)

Address : P.O. Box 586

Columbia, MD 21045

Phone No. : (301) 461-3127

Executive Director : Marcia Boyle, President

Contact Person : Marcia Boyle, President

Chapters/Satellites : 2: CA; OH/IN

Statement of Purpose :

The Immune Deficiency Foundation promotes and supports medical research and training for clinical treatment of immune deficiency diseases. The Foundation gathers, coordinates, and disseminates information concerning immune deficiency diseases and conducts public education campaigns.

Educational Materials:

Publication(s) : Immune Deficiency Diseases: An Overview
Immune Deficiency Diseases: A Guide for Nurses
The Immune Deficiency Diseases: A Statement of Case

Audiovisual(s) : Moment to Moment: The Story of Immune Deficiency

Newsletter(s) : IDF Newsletter (Annually)

Name of Organization : International Cystic Fibrosis (Mucoviscidosis) Association (I.C.F.(M).A.)

Address : 3567 East 49th Street
Cleveland, OH 44105

Phone No. : (216) 271-1100

Executive Director : Robert D. McCreery

Contact Person : Robert D. McCreery

Chapters/Satellites : Chapters in 40 different nations

Statement of Purpose :

The Association deals with all aspects of cystic fibrosis on a national and international level.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : International Institute for Visually Impaired, O-7, Inc.

Address : 1975 Rutgers
East Lansing, MI 48823

Phone No. : (517) 322-2666, (617) 332-4014

Executive Director : Sherry Raynor

Contact Person : Donna Heiner

Chapters/Satellites : 2: MI, MA

Statement of Purpose :

The Institute promotes and develops activities and programs pertaining to all areas of the growth, development, education, and welfare of pre-school visually impaired children.

Educational Materials:

Publication(s) : Make It - a booklet of toys and furniture plans designed by parents of multiply handicapped preschoolers.
Parent Packet
Get Ready . . . Get Set . . . Go

Audiovisual(s) : Move It

Newsletter(s) : VIP (Quarterly)

Name of Organization : International Joseph Diseases Foundation, Inc. (IJDF)

Address : P.O. Box 2550
Livermore, CA 94550

Phone No. : (415) 455-0706

Executive Director : Rose Marie Silva

Contact Person : Rose Marie Silva

Chapters/Satellites : 2: MA; CA

Statement of Purpose :

The International Joseph Diseases Foundation provides various services to those affected by or at-risk to inherit Joseph disease. Services include: free clinics, diagnostic services and treatment, social and medical services, genetic counseling, and networking of affected families. The Foundation promotes medical research and educates the medical profession and general public about Joseph disease so as to encourage accurate diagnosis and better treatment for those affected.

Educational Materials:

Publication(s) : Joseph Disease is a Genetic Motor System Disease

Audiovisual(s) : None

Newsletter(s) : Published quarterly when funding available

Name of Organization : International Rett's Syndrome Association (IRSA)

Address : 8511 Rose Marie Drive

Fort Washington, MD 20744

Phone No. : (301) 248-7031

Executive Director : Kathy Hunter

Contact Person : Kathy Hunter

Chapters/Satellites : Now forming

Statement of Purpose :

This newly formed organization began work in the summer of 1984. Its major emphasis is currently on helping to identify children with Rett syndrome and stimulating research. An additional concern is the collection and dissemination of accurate, objective information on the identification, cause, treatment, prognosis, frequency, and prevention of Rett syndrome. Family support is provided through networking systems in local areas. Chapters will be established in the future.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : Iron Overload Diseases Association, Inc.

Address : 224 Datura Street, Suite 912

West Palm Beach, FL 33401

Phone No. : (305) 659-5616 Night: (305) 689-6968

Executive Director : Roberta Crawford

Contact Person : Roberta Crawford

Chapters/Satellites : None

Statement of Purpose :

The Association provides counseling to patients and families, professional education through medical symposia and workshops, and public awareness by means of publications and information to the media. The Association encourages research, early diagnosis, and more effective treatment.

Educational Materials:

Publication(s) : Overload: An Ironic Disease
Iron Overload Alert

Audiovisual(s) : None

Newsletter(s) : Ironic Blood (Bimonthly)

Name of Organization : Juvenile Diabetes Foundation (JDF) International

Address : 60 Madison Avenue, 4th Floor

New York, NY 10010

Phone No. : (212) 889-7575

Executive Director : Gloria Pennington

Contact Person : Randi Sackheim

Chapters/Satellites : Chapters in United States of America, Canada, and several foreign countries

Statement of Purpose :

The Juvenile Diabetes Foundation International's primary objective is to raise funds to support research into the cause, cure, treatment, and prevention of diabetes and its complications. It also offers counseling and support to diabetics. The Foundation works with schools, service groups, and hospitals to promote public education and research.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : JDF: The Search for a Cure
We'll Find It
Low Blood Sugar Emergencies in the Diabetic Child

Newsletter(s) : Tie Lines (Quarterly)

Name of Organization : Laurence-Moon-Biedl Syndrome (LMBS) Support Network

Address : 122 Rolling Road

Lexington Park, MD 20653

Phone No. : (301) 863-5658

Executive Director : Barbara Mielcarek

Contact Person : Barbara Mielcarek

Chapters/Satellites : None

Statement of Purpose :

The LMBS Support Network was founded in 1984 for the purposes of increasing both public and professional awareness of LMBS, exchanging information about LMBS and its related problems, and providing emotional support to those affected. It also maintains current research data for health professionals and educational specialists.

Educational Materials:

Publication(s) : In progress

Audiovisual(s) : None

Newsletter(s) : In progress

Name of Organization : Leukemia Society of America, Inc.

Address : 733 Third Avenue

New York, NY 10017

Phone No. : (212) 573-8484

Executive Director : Peter N. Cakridas

Contact Person : M. Louise Toglia, Project Coordinator

Chapters/Satellites : 57 chapters throughout the United States

Statement of Purpose :

The Leukemia Society of America is dedicated solely to seeking the cause and eventual cure of leukemia and allied diseases. In this endeavor, it supports five major programs: research--in the form of grants to individual researchers; patient-aid--providing up to $750 per patient per year on an outpatient basis; public health education--through literature and various other media; professional education--through seminars, symposia, and publications; and community service--through a reciprocal communications program established with social service agencies and treatment facilities.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Society News (Six issues/year)

Name of Organization : Little People of America, Inc. (LPA)

Address : P.O. Box 633

San Bruno, CA 94066

Phone No. : (415) 589-0695

Executive Director : None

Contact Person : Harriet or Al Stickney

Chapters/Satellites : 37 throughout the United States

Statement of Purpose :

Little People of America is dedicated to helping people of short stature through fellowship, moral support, and the exchange of helpful information. LPA offers publications, educational and social programs, discussion groups, and workshops for short-statured individuals, their families, and the general public.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : LPA Today (Six issues/year)

Name of Organization : Lowe's Syndrome Association

Address : 222 Lincoln Street

West Lafayette, IN 47906

Phone No. : (317) 743-3634

Executive Director : Kaye McSpadden

Contact Person : Kaye McSpadden

Chapters/Satellites : None

Statement of Purpose :

The Lowe's Syndrome Association works to foster communication among families affected by Lowe syndrome, provide medical and educational information, and encourage research. The Association also hopes to promote a better understanding of Lowe syndrome and the potential of individuals with this condition.

Educational Materials:

Publication(s) : Parent Directory

Audiovisual(s) : None

Newsletter(s) : On the Beam (Triannually)

Name of Organization : The Lupus Foundation of America, Inc.

Address : 11921 A Olive Boulevard

St. Louis, MO 63141

Phone No. : (314) 872-9036

Executive Director : Roger Sturdevant, Vice President, Operations

Contact Person : Roger Sturdevant, Vice President, Operations

Chapters/Satellites : 87 throughout the United States

Statement of Purpose :

The Lupus Foundation of America is dedicated to providing patient information and services, increasing public awareness of lupus erythematosus, and funding research into its cause and cure.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : (Triannually)

Name of Organization : Malignant Hyperthermia Association of the United States (MHAUS)

Address : P.O. Box 3231
Darien, CT 06820

Phone No. : (203) 655-3007

Executive Director : Suellen Gallamore

Contact Person : Suellen Gallamore

Chapters/Satellites : None

Statement of Purpose :

MHAUS aims at reducing death and disability from malignant hyperthermia by providing educational and supportive services to MH-susceptible families and their physicians. The organization also sponsors limited research.

Educational Materials:

Publication(s) : Malignant Hyperthermia - The Anesthesiologist's Nightmare
Preventing Malignant Hyperthermia
Suggested Therapy for MH Emergency

Audiovisual(s) : None

Newsletter(s) : The Communicator (Quarterly)

Name of Organization : March of Dimes Birth Defects Foundation

Address : 1275 Mamaroneck Avenue

White Plains, NY 10605

Phone No. : (914) 428-7100

Executive Director : Charles L. Massey, President

Contact Person : Robert Goldberg, Assistant Director for Public Health

Chapters/Satellites : 440 chapters nationwide

Statement of Purpose :

Prevention of birth defects has been the goal of the March of Dimes for more than a quarter-century. Through a partnership of medical professionals and volunteers, the March of Dimes fights birth defects with an array of programs supported by the generosity of the American public.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Complete catalogue available upon request

Name of Organization : **Midwestern Celiac-Sprue Association (MCSA)**

Address : 2313 Rocklyn Drive, Suite 1

Des Moines, IA 50322

Phone No. : (515) 270-9689

Executive Director : Tracey Mohns, Executive Secretary

Contact Person : Tracey Mohns, Executive Secretary

Chapters/Satellites : Chapter Chairman and/or Resource Person in 28 states: RI; CT; NJ; NY; PA; MD; NC; FL; AL; TN; OH; IA; WI; SD; MN; IL; MO; KS; NE; AR; OK; TX; CO; UT; AZ; NM; CA; HI

Statement of Purpose :

MCSA provides materials on celiac-sprue disease to patients, families, health care professionals, and the general public. MCSA also serves as a vehicle for providing opportunities for mutual support to patients and families, keeps abreast of research, and provides dietary information about celiac-sprue and the gluten-free diet.

Educational Materials:

Publication(s) : Gluten-Free Drug Guide
GPL
TLC Pamphlet
Children's Survey Report
Directory of Doctors Referral Service

Audiovisual(s) : Set of 20 slides available for presentations on CS

Newsletter(s) : Lifeline (Quarterly)

Name of Organization : **Muscular Dystrophy Association (MDA)**

Address : 810 Seventh Avenue

New York, NY 10019

Phone No. : (212) 586-0808

Executive Director : Robert Ross

Contact Person : Ronald J. Schenkenberger

Chapters/Satellites : 240 MDA clinics throughout the United States

Statement of Purpose :

MDA provides a comprehensive patient and community services program. Its clinics provide diagnostic services and therapeutic and rehabilitative follow-up care as well as genetic, vocational, and social service counseling to patients and their families. Other services include repair of orthopedic appliances and transportation aid. MDA also supports an international research program to find the causes and effective treatments of muscular dystrophy and related neuromuscular disorders.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : MDA News Magazine (Quarterly)

Name of Organization : **Myasthenia Gravis Foundation, Inc. (MGF)**

Address : 15 East 26th Street, Suite 1603

New York, NY 10010

Phone No. : (212) 889-8157

Executive Director : Robert S. McKanna

Contact Person : Robert S. McKanna

Chapters/Satellites : 48: AL (2); AZ; CA (2); CO; CT; DC; FL (3); GA; IL; IN (2); IA; KY; LA (2); MD; MA; MI (2); MN; MO; NE; NJ; NY (2); NC; OH (3); OK; PA; RI; SD; TX (5); UT; VA; WA; WV (2); WI

Statement of Purpose :

The Myasthenia Gravis Foundation is dedicated to the detection, treatment, and cure of myasthenia gravis (MG). Foundation programs include: public and professional information and education; patient services, from drug banks to self-help groups; research grants and fellowships; annual scientific sessions; and quinquennial international symposia.

Educational Materials:

Publication(s) : MG - the Disease
A Case History
Help Is On The Way
MG and the MGF
What is Myasthenia Gravis?
Who Am I?
Nurses' Manual (English and Spanish versions)
Facts About MG
Physicians' Manual (English and Spanish versions)

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : **Myoclonus Families United**

Address : 1564 East 34th Street

Brooklyn, NY 11234

Phone No. : (718) 252-2133

Executive Director : Sharon Dobkin

Contact Person : Sharon Dobkin

Chapters/Satellites : None

Statement of Purpose :

Myoclonus Families United is concerned with supporting affected individuals and their families. The group provides a self-help directory, physician referrals, and testifies to Congress as an advocate of increased national support.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : National Amyotrophic Lateral Sclerosis (ALS) Foundation, Inc.

Address : 185 Madison Avenue
New York, NY 10016

Phone No. : (212) 679-4016

Executive Director : Rochelle Moss

Contact Person : Rochelle Moss

Chapters/Satellites : 10: FL (2); IN; MI; NJ (2); NY; OH; PA (2)

Statement of Purpose :

The National Amyotrophic Lateral Sclerosis Foundation stimulates and supports research investigating the cause and cure of ALS (Lou Gehrig's disease). The organization's program includes research funding, patient services, public and professional education, chapter development, and the establishment of ALS clinical service centers nationwide.

Educational Materials:

Publication(s) : Home Care for the Patient with Amyotrophic Lateral Sclerosis
What is ALS? Some Questions and Answers
ETRAN Communicator (descriptive brochure)

Audiovisual(s) : None

Newsletter(s) : National ALS Update (Quarterly)

Name of Organization : **National Association for the Craniofacially Handicapped**

Address : P.O. Box 11082
Chattanooga, TN 37401

Phone No. : (615) 266-1632

Executive Director : Mary Jane Torrance

Contact Person : Mary Jane Torrance

Chapters/Satellites : None

Statement of Purpose :

The National Association for the Craniofacially Handicapped provides referral and financial aid to qualified applicants based on financial need. Liaison with support groups is also provided.

Educational Materials:

Publication(s) : Various brochures available

Audiovisual(s) : A Face in the Crowd

Newsletter(s) : Faces (Occasionally)

Name of Organization : The National Association for Parents of the Visually Impaired, Inc. (NAPVI)

Address : P.O. Box 180806
Austin, TX 78718

Phone No. : (512) 459-6651

Executive Director : Lee W. Robinson, Ed.D.

Contact Person : Elaine Moses, President

Chapters/Satellites : 5 affiliates: CA; PA; OH; NE; NY

Statement of Purpose :

The National Association for Parents of the Visually Impaired is a broadly based organization whose membership includes parents, parent organizations, agencies, and other persons dedicated to supporting the parents of visually impaired children. In an effort to reach as many parents as possible, the American Foundation for the Blind helped form NAPVI in 1980.

Educational Materials:

Publication(s) : Take Charge! A Guide to Resources for Parents of the Visually Impaired
How to Pack 'Em In: A Guide to Planning Workshops
A Guide to Library Services for Teachers of the Visually Impaired
Parents to the Rescue
Your Child's Information Journal

Audiovisual(s) : None

Newsletter(s) : Awareness (Quarterly)

Name of Organization : **National Association for Sickle Cell Disease, Inc. (NASCD)**

Address : 3460 Wilshire Boulevard, Suite 1012
Los Angeles, CA 90010

Phone No. : (213) 936-7205 (800) 421-8453

Executive Director : Dorothy Boswell

Contact Person : Dorothy Boswell

Chapters/Satellites : 86 affiliates

Statement of Purpose :

This organization prepares and distributes educational materials to increase awareness of the impact of sickle cell disease. It is also dedicated to promoting the resolution of issues that might adversely affect patients. It actively participates in national and regional conferences, and in the development of local chapters.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Sickle Cell News (Quarterly)

Name of Organization : National Association for Visually Handicapped

Address : 305 East 24th Street, 17-C

New York, NY 10010

Phone No. : (212) 889-3141

Executive Director : Lorraine H. Marchi

Contact Person : Lorraine H. Marchi

Chapters/Satellites : None

Statement of Purpose :

The Association provides information, referral, counseling, and guidance to the partially sighted, their families, and the professionals, paraprofessionals, and business community working with them. Informational booklets and brochures, large-print books for pleasure reading, textbooks, and testing material are available for adults and children.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Seeing Clearly (adults) (One or two issues/year)
In-Focus (children) (One or two issues/year)

Name of Organization : **National Association of Radiation Survivors (NARS)**

Address : 78 El Camino Real

Berkeley, CA 94705

Phone No. : (415) 658-6056 (415) 652-4400, x441

Executive Director : Dorothy Legarreta, Ph.D.

Contact Person : Dorothy Legarreta, Ph.D.

Chapters/Satellites : 13: AZ; CO; ME; MO; MS; NJ; NM; NV; NY; OR; UT; VA; CA

Statement of Purpose :

The Association was founded in 1982 to provide medical, legal, and mutual support to veterans and civilians exposed to ionizing radiation in the Nuclear Weapons Testing Program since 1943. It also supports research into late onset effects of exposure, including genetic defects. With 13 chapters nationwide, it is very active in bringing the issue to light, appearing in documentaries, spearheading legal claims, and testifying before Congress. The Association offers an extensive network of health and legal professionals, as well as a computer-based databank with statistics on every military exposure site.

Educational Materials:

Publication(s) : None

Audiovisual(s) : NARS slide show
Shadow of Death (photography show)

Newsletter(s) : (Quarterly)

Name of Organization : **National Ataxia Foundation**

Address : 600 Twelve Oaks Center

15500 Wayzata Boulevard

Wayzata, MN 55391

Phone No. : (612) 473-7666

Executive Director : Donna Gruetzmacher, Patient Services Director

Contact Person : Donna Gruetzmacher, Patient Services Director

Chapters/Satellites : 12: AZ; MD; PA; SD; LA; TN; MS; NC; WA; MN (2); IA

Statement of Purpose :

The National Ataxia Foundation strives to combat all types of hereditary ataxia and closely related disorders, such as hereditary spastic paraplegia, ataxia telangiectasia, and Charcot-Marie-Tooth syndrome. It offers clinical services, information, referrals, and housing for the disabled.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Generations (Quarterly)

Name of Organization : National Down Syndrome Congress

Address : 1640 West Roosevelt Road

Chicago, IL 60608

Phone No. : (312) 226-0416 (800) 446-3835 (Outside IL)

Executive Director : Diane M. Crutcher

Contact Person : Diane M. Crutcher

Chapters/Satellites : 600 across the United States, with contacts in 40 foreign countries

Statement of Purpose :

The National Down Syndrome Congress serves families through adoption facilitation, annual conventions, publications, media review, educational guidelines, legislative and public awareness, parent group roster, and research monitoring. Adolescents and adults with down syndrome, and their siblings, are offered support in conjunction with these coordinated services.

Educational Materials:

Publication(s) : Down Syndrome (available in English, Spanish, or Portuguese)
Educational Guidelines

Audiovisual(s) : None

Newsletter(s) : Down Syndrome News (Ten issues/year)

Name of Organization : National Down Syndrome Society

Address : 70 West 40th Street

New York, NY 10018

Phone No. : (212) 764-3070 (800) 221-4602

Executive Director : Donna M. Rosenthal

Contact Person : Donna M. Rosenthal

Chapters/Satellites : None

Statement of Purpose :

The National Down Syndrome Society was established to create public awareness of Down syndrome, to support research addressing the causes and amelioration of this genetic defect, and to provide services for families and individuals with Down syndrome. The services include educational literature, and a resource directory of support groups and early intervention programs. The Society awards two-year $50,000 grants to researchers concentrating on Down syndrome.

Educational Materials:

Publication(s) : This Baby Needs You Even More
Questions and Answers about Down Syndrome
Fact Sheet: Down Syndrome

Audiovisual(s) : Gifts of Love

Newsletter(s) : National Down Syndrome Society Update (Biannually)

Name of Organization : National Easter Seal Society

Address : 2023 West Ogden Avenue

Chicago, IL 60612

Phone No. : (312) 243-8400

Executive Director : John Garrison

Contact Person : Jan Bakker

Chapters/Satellites : 820+ state and local affiliates

Statement of Purpose :

The National Easter Seal Society, dating back to 1919, pioneered the attempt to identify needs of disabled people and provide rehabilitation services. Direct services are provided to persons with disabilities and their families through more than 820 state and local affiliates, operating some 2000 facilities and programs across the country. The Society is also concerned with advocacy, public health education, research, and providing grants for investigation into the causes of disabling conditions and the rehabilitation of disabled people.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Communicator (Quarterly)

Name of Organization : National Foundation for Ectodermal Dysplasias (NFED)

Address : 108 North First Street, Suite 311

Mascoutah, IL 62258

Phone No. : (618) 566-2020

Executive Director : Mary Kaye Richter

Contact Person : Mary Kaye Richter

Chapters/Satellites : None

Statement of Purpose :

The NFED provides support and information services to families, patients, and medical professionals concerned with the needs of individuals affected by the ectodermal dysplasia (ED) syndromes. Research projects are encouraged and cooperative efforts undertaken. The ultimate goal is to assure all ED patients not only a normal life span but a normal lifestyle as well. The NFED provides information services through its monthly newsletter and other publications. Referrals for treatment are made and a scientific advisory board is available to provide diagnostic information and assist with treatment when necessary.

Educational Materials:

Publication(s) : NFED
A Family Guide to the Ectodermal Dysplasias

Audiovisual(s) : A First Look at the Ectodermal Dysplasias

Newsletter(s) : NFED (Monthly)

Name of Organization : The National Foundation for Jewish Genetic Diseases

Address : 250 Park Avenue, Suite 1000

New York, NY 10177

Phone No. : (212) 682-5550

Executive Director : Joan Samsen

Contact Person : Melissa Anne Gill

Chapters/Satellites : None

Statement of Purpose :

The National Foundation for Jewish Genetic Diseases was created to raise funds for and inform the public about genetic diseases affecting descendants of Eastern and Central European Jews. Materials concerning the following Jewish genetic diseases are available upon request: familial dysautonomia, torsion dystonia, Gaucher disease, and mucolipidosis IV.

Educational Materials:

Publication(s) : Fact Sheet: You Have a Right to Know . . . About Jewish Genetic Diseases
Genetic Disease Among Ashkenazi Jews edited by Richard M. Goodman, M.D., and Arno G. Motulsky
Genetic Disorders Among the Jewish People by Richard M. Goodman, M.D.

Audiovisual(s) : The Tragic Legacy

Newsletter(s) : Genetically Speaking (Biannually)

Name of Organization : **National Fragile X Support Group**

Address : Route 8, Box 109

Bridgeton, NJ 08302

Phone No. : (609) 455-7508

Executive Director : Lois Garrison

Contact Person : Lois Garrison

Chapters/Satellites : None

Statement of Purpose :

The National Fragile X Support Group, established in 1984, works to educate the medical community about diagnostic variations, and promotes public awareness. It offers pertinent materials in response to mail or phone requests. The Support Group works closely with the Institute for Basic Research in Staten Island, NY.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : National Gaucher Foundation (NGF)

Address : 1424 K Street, NW, 4th Floor

Washington, DC 20005

Phone No. : (202) 393-2777

Executive Director : Mary Nathan

Contact Person : Mary Nathan

Chapters/Satellites : Gaucher's Disease Registry (Orange, CA)

Statement of Purpose :

The National Gaucher Foundation works toward finding a remedy and viable treatment program for Gaucher disease. This goal is accomplished by promoting and supporting medical research and clinical programs enhancing the current understanding of the causes and symptoms of Gaucher disease. Services provided include answering phone and mail information requests, and supporting individuals and families through a family support network. The Foundation also serves as a clearinghouse for donations and a recipient of grant applications.

Educational Materials:

Publication(s) : None

Audiovisual(s) : Gaucher's Disease: Coping, Caring and Searching for a Cure

Newsletter(s) : Gaucher's Disease Registry Newsletter (Bimonthly)

Name of Organization : **National Genetics Foundation, Inc.**

Address : 555 West 57th Street

New York, NY 10019

Phone No. : (212) 586-5800

Executive Director : Ruth Y. Berini

Contact Person : Eva Kahn, Genetic Counselor

Chapters/Satellites : None

Statement of Purpose :

The National Genetics Foundation develops and implements delivery systems to incorporate clinical genetics advances into health care for utilization in diagnosis, treatment, prevention, and counseling for both common and rare disorders with genetic components. Through its Family Health Profile Analyses, it provides family health surveillance for such disorders. The emphasis is on identification of individuals who can benefit from recent advances in therapeutic and preventive measures.

Educational Materials:

Publication(s) : How Genetic Disease Can Affect You and Your Family
Can Genetic Counseling Help You?
For the Concerned Couple Planning a Family
Should You Consider Amniocentesis?
Family Health Profile Analysis Order Form

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : **The National Hemophilia Foundation (NHF)**

Address : The Soho Building

110 Greene Street, Room 406

New York, NY 10002

Phone No. : (212) 219-8180

Executive Director : Alan P. Brownstein

Contact Person : Lisa Flam

Chapters/Satellites : 48 throughout the United States

Statement of Purpose :

NHF promotes opportunities to improve the quality of life of all hemophilia and blood disorder patients. Its primary avenues include employment counseling, home therapy, and advocacy affecting public policy.

Educational Materials:

Publication(s) : Complete catalogue available on request

Audiovisual(s) : None

Newsletter(s) : News Notes (Quarterly)
Nursing Network News (Biannually)
Psychosocial News (Biannually)

Name of Organization : **National Huntington's Disease Association, Inc.**

Address : 1182 Broadway, Suite #402

New York, NY 10001

Phone No. : (212) 684-2781

Executive Director : Ruby Horansky

Contact Person : Ruby Horansky

Chapters/Satellites : 85 throughout the United States

Statement of Purpose :

The Association supports scientific research into the cause, treatment, and cure of Huntington disease (HD); maintains a network of social services personnel throughout the country; and provides educational material for the lay public and health care professionals.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Huntington's Disease

Newsletter(s) : HD News (Quarterly)

Name of Organization : The National Hydrocephalus Foundation (NHF)

Address : Route 1, River Road, Box 210 A

Joliet, IL 60436

Phone No. : (815) 467-6548

Executive Director : James Mazzetti

Contact Person : James Mazzetti

Chapters/Satellites : 3: TX; OH; WI

Statement of Purpose :

The purpose of the National Hydrocephalus Foundation is threefold: (1) to offer help and information to parents of children with hydrocephalus, (2) to unite adults with hydrocephalus, and (3) to promote treatment research, including shunt development. The foundation is sensitive to families' needs for medical insurance and for erasing the stigma of hydrocephalus. Other services include a parent referral system, a newsletter, symposia, and informal meetings. Public education is encouraged through pamphlets and awareness of Public Law 94-142.

Educational Materials:

Publication(s) : Problems of Hydrocephalus
Introduction to Hydrocephalus

Audiovisual(s) : None

Newsletter(s) : (Triannually)

Name of Organization : The National Ichthyosis Foundation

Address : P.O. Box 252

Belmont, CA 94002

Phone No. : (415) 591-1653 (415) 348-6309

Executive Director : Susan Nye De Haan, Co-president
Charles L. Eichorn, Co-president

Contact Person : Susan Nye De Haan, Co-president
RR#1
Filer, ID 83328
(208) 326-5154

Chapters/Satellites : 15: CA (4); CT, MI; MN; NC; NY (2); OK; PA; TX; VA; British Columbia

Statement of Purpose :

The Foundation works for the benefit and education of its members and the public regarding medical, psychologial and social aspects of ichthyosis.

Educational Materials:

Publication(s) : Information Packets
"How To" manual for chapter organizing

Audiovisual(s) : None

Newsletter(s) : The Ichthyosis Focus (Six issues/year)

Name of Organization : **National Information Center on Deafness**

Gallaudet College

Address : 800 Florida Avenue, NE

Washington, DC 20002

Phone No. : (202) 651-5109 (Voice) (202) 651-5976 (TDD)

Executive Director : Loraine DiPietro

Contact Person : Arlynn Joffe
Cheryl Hennessy

Chapters/Satellites : None

Statement of Purpose :

The National Information Center on Deafness provides up-to-date, accurate information and referrals on questions relating to deafness, education of deaf students, research, demographics, law, technology, and barrier-free design. The Center provides information to parents, professionals, and the general public on all aspects of deafness.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : None

Name of Organization : National Kidney Foundation, Inc.

Address : 2 Park Avenue

New York, NY 10016

Phone No. : (212) 889-2210

Executive Director : John Davis

Contact Person : Dolph Chianchiano

Chapters/Satellites : 50 affiliates throughout the United States

Statement of Purpose :

The National Kidney Foundation provides patient publications, professional materials, transportation to facilities, and referrals in an attempt to improve the lives of patients. The Foundation also supports research into the prevention and cure of kidney and urinary tract diseases.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Kidney '85 (Five issues/year)

Name of Organization : **National Lupus Erythematosus Foundation, Inc.**

Address : 5430 Van Nuys Boulevard, Suite 206

Van Nuys, CA 91401

Phone No. : (213) 885-8787

Executive Director : Marlene Rothstein-Bane

Contact Person : Cathy Moulton

Chapters/Satellites : None

Statement of Purpose :

The Foundation provides information and education concerning lupus erythematosus to interested persons of all ages, as well as encouraging research into this disease. Lupus patients and their families receive counseling and medical referrals.

Educational Materials:

Publication(s) : Lupus

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : **National Lymphatic and Venous Diseases Association**

Address : P.O. Box 80

Cambridge, MA 02140

Phone No. : (617) 784-4104

Executive Director : Louise Chereski

Contact Person : Ellen Fox

Chapters/Satellites : None

Statement of Purpose :

The National Lymphatic and Venous Diseases Association was established to provide self-help, support research, and service patients with lymphedema and Mulroy disease. It provides informational materials, physician referrals, and quarterly meetings.

Educational Materials:

Publication(s) : Fact Sheet

Audiovisual(s) : None

Newsletter(s) : (Triannually)

Name of Organization : **National Marfan Foundation**

Address : 54 Irma Avenue

Port Washington, NY 11050

Phone No. : (516) 883-8712

Executive Director : Priscilla Ciccariello

Contact Person : Priscilla Ciccariello

Chapters/Satellites : 7: CA; LA; PA; NY; NJ; MD; DC

Statement of Purpose :

The National Marfan Foundation has a threefold purpose: (1) to provide accurate and timely information about this condition to patients, family members, and physicians; (2) to provide means for patients and relatives to share experiences, support one another, and improve their medical care; and (3) to support and foster research.

Educational Materials:

Publication(s) : The Marfan Syndrome (2nd ed.) by Drs. Reed E. Pyeritz and Julia Conant
How John Was Unique by Joe and Nancy Hathaway (Children's picture book)

Audiovisual(s) : 4 one-hour long tapes of National meeting 9/8/84, 'Report on Research of the Marfan Syndrome"
1 one-hour long tape of TV talk program

Newsletter(s) : Connective Issues (Six issues/year)

Name of Organization : **National Mucopolysaccharidoses (MPS) Society, Inc.**

Address : 17 Kraemer Street

Hicksville, NY 11801

Phone No. : (516) 931-6338

Executive Director : Maria Capobianco

Contact Person : Maria Capobianco

Chapters/Satellites : None

Statement of Purpose :

Since 1983, the National MPS Society has existed at the local level as the MPS Society. It is now expanding to the national level, incorporating chapters nationwide. Formed by parents of MPS children, the Society is primarily dedicated to serving parents through support, networking, and physician referrals.

Educational Materials:

Publication(s) : What is MPS?

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : **National Multiple Sclerosis Society**

Address : 205 East 42nd Street

New York, NY 10017

Phone No. : (212) 986-3240

Executive Director : Robert J. Slater, M.D.

Contact Person : Robert J. Slater, M.D.

Chapters/Satellites : 40 throughout the United States

Statement of Purpose :

The National Multiple Sclerosis (MS) Society serves affected individuals through many channels such as research support. Current information and counseling are available to MS patients, their families, and to interested parties. Other services include advocacy, referral, and equipment loans.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Inside MS (Quarterly)

Name of Organization : **National Myoclonus Foundation**

Address : 845 Third Avenue, Fourth Floor

New York, NY 10022

Phone No. : (212) 758-5656

Executive Director : Burtin J. Diamond

Contact Person : Burtin J. Diamond

Chapters/Satellites : None

Statement of Purpose :

This organization, founded in 1975, raises funds to defer medication costs. The Foundation responds to telephone and mail requests and provides patient referrals.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : **The National Neurofibromatosis Foundation, Inc. (NF)**

Address : 70 West 40th Street, Fourth Floor

New York, NY 10018

Phone No. : (212) 869-9034

Executive Director : Felice Yahr

Contact Person : Felice Yahr

Chapters/Satellites : 17: AZ; CA; FL; IL; IA; LA; MA; DC area; MI; MO; NJ; NY; OH; OR; PA; UT; VA

Statement of Purpose :

The National Neurofibromatosis Foundation responds to the needs of people with neurofibromatosis and their families. It also acts as a resource for medical and health professionals. Other concerns are educating the general public and supporting research through small grants.

Educational Materials:

Publication(s) : Neurofibromatosis: Information for Patients and Families

Audiovisual(s) : None

Newsletter(s) : Newsletter (Quarterly)
Research Newsletter (Quarterly)

Name of Organization : **National Organization for Albinism and Hypopigmentation (NOAH)**

Address : 919 Walnut Street, Room 400
Philadelphia, PA 19107

Phone No. : (215) 627-3501

Executive Director : None

Contact Person : Janice L. Knuth, President

Chapters/Satellites : 3: PA; DC area; Upper Midwest area

Statement of Purpose :

NOAH distributes information on albinism and hypopigmentation, and provides support for individuals and families. Albinism and hypopigmentation often mean isolation for individuals and families with these conditions. NOAH seeks to overcome this isolation by spreading understanding through mutual sharing. It also promotes public and professional education regarding albinism and hypopigmentation and funds research to improve diagnosis and treatment.

Educational Materials:

Publication(s) : In progress

Audiovisual(s) : None

Newsletter(s) : NOAH News (Biannually)

Name of Organization : **National Organization for Rare Disorders, Inc.**

(NORD)

Address : Fairwood Professional Building

100 Route 37

New Fairfield, CT 06812

Phone No. : (203) 746-6518

Executive Director : Abby Meyers

Contact Person : Abby Meyers

Chapters/Satellites : None

Statement of Purpose :

The organization is a coalition of voluntary health agencies, medical researchers and private citizens dedicated to the interests of individuals with rare disorders. Among its many goals are: educating the public on the existence and treatment of rare disorders; fostering communication between rare disease voluntary agencies and government bodies; and advocating for people with rare disorders who are otherwise not represented. The organization strongly encourages research and actively disseminates information about orphan drugs and rare disorders. Ultimately concerned with the physical and emotional well-being of persons with rare diseases, this organization strives to ensure their proper representation.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : The Orphan Disease Update (Quarterly)

Name of Organization : **National Scoliosis Foundation, Inc.**

Address : P.O. Box 547, 93 Concord Avenue

Belmont, MA 02178

Phone No. : (617) 489-0888

Executive Director : Janet T. Khattab

Contact Person : Janet T. Khattab

Chapters/Satellites : 2: MI; TX

Statement of Purpose :

The National Scoliosis Foundation alerts the public to the potentially serious health problems associated with abnormal spinal curvatures--scoliosis, kyphosis, and lordosis--and develops programs leading to early detection and treatment. These goals are accomplished through literature and audiovisuals, as well as direction, guidance, and material assistance for implementing or improving statewide screening programs in schools. Networking is another priority for the Foundation. Referral services for parents, patients, schools, health and education agencies, and the medical profession are also offered.

Educational Materials:

Publication(s) : In 30 Seconds You Can Change the Shape of Your Child's Life
Una Persona de Cada 10 Sufre de Escoliosis

Audiovisual(s) : Growing Straighter and Stronger

Newsletter(s) : The Spinal Connection (Biannually)

Name of Organization : **National Sickle Cell Clinics Foundation, Inc.**

Address : P.O. Box 8095

Houston, TX 77288

Phone No. : (713) 527-8236

Executive Director : Darnelle' D. Pinkard

Contact Person : Darnelle' D. Pinkard

Chapters/Satellites : None

Statement of Purpose :

The Foundation's objectives are twofold: 1) to organize, operate, and maintain a national organization concerned with the continuation of sickle cell education, screening, and counseling clinics at a quality level; and 2) to improve the life status of populations at-risk for the sickling gene and related hemoglobinopathies.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : Hemo-Globe (Quarterly)

Name of Organization : National Society for Children and Adults with Autism

Address : 1234 Massachusetts Avenue, NW
Washington, DC 20005

Phone No. : (202) 783-0125

Executive Director : Roy Morgan

Contact Person : Roy Morgan

Chapters/Satellites : 175 chapters and state societies throughout the United States

Statement of Purpose :

National Society for Children and Adults with Autism is the only national volunteer organization devoted solely to the well-being of individuals with autism. The Society maintains a community-based network with 6000 members nationwide. The organization is governed by a national board of seventeen directors elected by the general membership, complemented by a Professional Advisory Board composed of scientific investigators, educators, and experts in research disciplines relevant to autism.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Advocate (Six issues/year)

Name of Organization : **National Support Group for Arthrogryposis Multiplex Congenita (AVENUES)**

Address : P.O. Box 5192

Sonora, CA 95370

Phone No. : (209) 533-1468

Executive Director : Mary Anne Schmidt

Contact Person : Mary Anne Schmidt

Chapters/Satellites : None

Statement of Purpose :

AVENUES was founded in 1980 for the purpose of sharing information on arthrogryposis multiplex congenita. Its newsletter highlights new advances in research, treatment, and patient aids.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : Avenues (Biannually)

Name of Organization : **National Support Group for Exstrophy**

Address : 5075 Medhurst Street

Solon, OH 44139

Phone No. : (216) 248-6851

Executive Director : Penny Boross

Contact Person : Denise Womack

Chapters/Satellites : None

Statement of Purpose :

This group helps in the everyday care of children and adults with exstrophy and networks them with others similarly affected. It offers non-medical advice and support, as well as physician referrals.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : Parents for Exstrophy (as funds are available)

Name of Organization : The National Tay-Sachs and Allied Diseases Association, Inc. (NTSAD)

Address : 92 Washington Avenue
Cedarhurst, NY 11516

Phone No. : (516) 569-4300

Executive Director : Jane Birnbaum

Contact Person : Jane Birnbaum

Chapters/Satellites : 12: FL; New England; IL; TX; NJ; NY; Delaware Valley; DC/MD/VA; CA; RI; South Africa; England

Statement of Purpose :

The Association develops, coordinates, and implements medical, public relations, educational, and fund-raising programs related to the prevention of and research into Tay-Sachs and allied lysosomal and neurological diseases. The Association also supports genetic screening programs on a national level and provides educational materials to the public and health professionals. New parents receive emotional support and practical guidance on a personal, non-professional level through the Parent Peer Group Network.

Educational Materials:

Publication(s) : Test Center Directory
What Every Family Should Know
One Day at a Time
Prevent a Tragedy

Audiovisual(s) : Sound/slide presentation

Newsletter(s) : Breakthrough (Biannually)

Name of Organization : National Tuberous Sclerosis Association, Inc. (NTSA)

Address : Box 612
Winfield, IL 60190

Phone No. : (312) 668-0787

Executive Director : Linda Ham, Project Coordinator

Contact Person : Linda Ham, Project Coordinator

Chapters/Satellites : 46 State Representatives function as referral resources for physicians and affected families in 35 states and Canada

Statement of Purpose :

NTSA dedicates its resources to providing a better quality of life for those affected with tuberous sclerosis by encouraging and sponsoring research. Education is of utmost importance; NTSA provides printed material attempting to cover many of the latest treatment techniques. Various services offered include a Pen Pal program, parent-to-parent contact, and a support group network.

Educational Materials:

Publication(s) : None

Audiovisual(s) : Slide presentation

Newsletter(s) : (Quarterly)

Name of Organization : The Organic Acidemia Association

Address : 1532 South 87th Street

Kansas City, KS 66111

Phone No. : (913) 422-7080

Executive Director : Lorie Asten

Contact Person : Lorie Asten

Chapters/Satellites : 1: United Kingdom

Statement of Purpose :

The Organic Acidemia Association was established in 1982 to encourage consistent communication and support among families and professionals dealing with organic acidemias and related rare metabolic disorders. Presently, it offers referrals and a membership roster for networking purposes. A literature resource library is kept up-to-date on pertinent issues concerning organic acidemias.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : Osteogenesis Imperfecta Foundation, Inc. (OIF)

Address : P.O. Box 838

Manchester, NH 03105

Phone No. : (603) 623-0934

Executive Director : Gemma Geisman

Contact Person : Gemma Geisman

Chapters/Satellites : 12 throughout the United States

Statement of Purpose :

The Osteogenesis Imperfecta Foundation is dedicated to alleviating the problems associated with osteogenesis imperfecta (OI). Since its founding in 1970 by a small group of parents to stimulate interest in treatment for OI, its purposes have expanded to include: (1) information gathering and sharing with OI patients, families, and professionals; and (2) research encouragement and support. It offers free literature, including a quarterly newsletter, and telephone counseling and referrals. Support groups and local chapters provide other contact services.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Breakthrough (Quarterly)

Name of Organization : The Paget's Disease Foundation, Inc. (PDF)

Address : P.O. Box 2772

Brooklyn, NY 11202

Phone No. : (718) 596-1043

Executive Director : Anne Kone

Contact Person : Anne Kone

Chapters/Satellites : None

Statement of Purpose :

The Paget's Disease Foundation is dedicated to assisting patients suffering from Paget disease and similar disorders. The Foundation has provided free educational materials to patients and medical professionals since its establishment in 1978. An Advisory Medical Panel assists with physician referrals and consultations.

Educational Materials:

Publication(s) : Understanding Paget's Disease
Who Cares about People with Paget's Disease?

Audiovisual(s) : None

Newsletter(s) : The P.D.F. Update (Biannually)

Name of Organization : **Parents of Dwarfed Children**

Address : 11524 Colt Terrace

Silver Spring, MD 20902

Phone No. : (301) 649-3275

Executive Director : Margaret B. Badner

Contact Person : Margaret B. Badner

Chapters/Satellites : None

Statement of Purpose :

Parents of Dwarfed Children is a corporation of parents of short-statured children. Their aim is to help other parents who have recently learned that their child has a form of dwarfism.

Educational Materials:

Publication(s) : Brochure

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : Parkinson's Disease Foundation

Address : William Black Medical Research Building
Columbia-Presbyterian Medical Center
640-650 West 168th Street
New York, NY 10032

Phone No. : (212) 923-4700

Executive Director : Dinah T. Orr

Contact Person : Dinah T. Orr

Chapters/Satellites : None

Statement of Purpose :

In 1957, William Black established the Parkinson's Disease Foundation for the purpose of finding the cause and cure for this debilitating disease. Today, work continues in a building named for the founder at Columbia University Medical Center. In addition to funding this in-house research, the Foundation offers symposia, medical fellowships, and grants to research departments of other universities and hospitals. The Foundation also serves as a source of information to patients and physicians on all aspects of Parkinson disease and other diseases of the basal ganglia.

Educational Materials:

Publication(s) : The Parkinson Patient at Home
Exercises for the Parkinson Patient
Parkinson's Disease: Progress, Promise and Hope!

Audiovisual(s) : Management of Parkinson's Disease and Syndrome of Levodopa

Newsletter(s) : (Triannually)

Name of Organization : Polycystic Kidney Research (PKR) Foundation

Address : 127 West Tenth Street

Kansas City, MO 64105

Phone No. : (816) 421-1869

Executive Director : Jean Bacon

Contact Person : Elcie Custer, Executive Secretary

Chapters/Satellites : None

Statement of Purpose :

The PKR Foundation is dedicated to finding the cause of and cure for polycystic kidney disease. It offers support and information to affected persons and families, and educates the general public. The Foundation assists research by enlisting financial support for outstanding research projects, educating family and friends of affected persons about the disease process, and promoting coordination within the scientific community to ensure the maximal utilization of scarce resources.

Educational Materials:

Publication(s) : Polycystic Kidney Disease?
Problems in Diagnosis and Management of Polycystic Kidney Disease

Audiovisual(s) : None

Newsletter(s) : PKR Progress (Quarterly)

Name of Organization : Prader-Willi Syndrome Association (PWSA)

Address : 5515 Malibu Drive

Edina, MN 55436

Phone No. : (612) 933-0113

Executive Director : Marge A. Wett

Contact Person : Marge A. Wett

Chapters/Satellites : 12: CT; NY; KY; MO; PA; MN; CO; MA; OH; IN; TX; MI

Statement of Purpose :

The Association, providing a vehicle of communication for parents, professionals, and other interested citizens, is dedicated to the sharing of experiences of coping with Prader-Willi syndrome. The publication of informational and educational materials for parents and professionals is one of its major focuses. Consultation information is also available.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : PWSA Audio/Visual Presentation (60 slides and cassette tape)
Oakwood Residence: A Home for People with PWS

Newsletter(s) : The Gathered View (Bimonthly)

Name of Organization : **Prescription Parents, Inc.**

Address : P.O. Box 426

Quincy, MA 02269

Phone No. : (617) 479-2463

Executive Director : Barbara Seltzer, President

Contact Person : Mary Carey

Chapters/Satellites : 1: Worcester, MA

Statement of Purpose :

Prescription Parents, founded in 1973, directs its services to parents of children born with cleft lip and/or palate and to affected adults. It provides parental assistance through discussion groups, professional speakers and publications, monitors state and local agencies, and provides information and education to encourage research efforts.

Educational Materials:

Publication(s) : Perspectives Concerning Cleft Lip and Cleft Palate
Caring for Your Newborn
Hearing and Behavior: In Children Born with Cleft Palate

Audiovisual(s) : Audiotape: Conversations among young adults who were born with cleft lip and/or palate.

Newsletter(s) : (Two-three issues/year)

Name of Organization : Progeria International Registry

Department of Human Genetics

Address : 1050 Forest Hill Road

Staten Island, NY 10314

Phone No. : (718) 494-5230

Executive Director : W. Ted Brown, M.D., Ph.D.

Contact Person : W. Ted Brown, M.D., Ph.D.

Chapters/Satellites : None

Statement of Purpose :

The Registry attempts to identify all persons affected with progeria. Information, counseling, and mutual support is then made available to patients and their families. Statistical analyses on these data also serve to further research.

Educational Materials:

Publication(s) : Fact Sheet

Audiovisual(s) : None

Newsletter(s) : (Occasionally)

Name of Organization : **Rehabilitation International (RI)**

Address : 25 East 21st Street

New York, NY 10010

Phone No. : (212) 420-1500

Executive Director : Susan R. Hammerman, Secretary General

Contact Person : Susan R. Hammerman, Secretary General

Chapters/Satellites : 135 member organizations in 77 countries

Statement of Purpose :

Founded in 1922, the organization has grown to more than 135 member groups in 77 countries in all regions of the world. Through its network of relationships with the United Nations, governments, and member organizations, RI serves as a main source of action to change attitudes, eliminate social and physical barriers, and assist in the full participation of disabled people in society. It holds quadrennial congresses, provides technical assistance for programs, and operates international and regional information services in New York, Heidelberg, Mexico City, and Kuwait.

Educational Materials:

Publication(s) : International Rehabilitation Review
International Journal of Rehabilitation Research
Rehabilitacion (in Spanish)

Audiovisual(s) : None

Newsletter(s) : None

Name of Organization : **Rehabilitation International USA (RIUSA)**

Address : 1123 Broadway

New York, NY 10010

Phone No. : (212) 620-4040

Executive Director : Philip F. Puleio, Ph.D., National Secretary

Contact Person : Jean O'Neill

Chapters/Satellites : None

Statement of Purpose :

RIUSA's mission is to represent the United States in the worldwide network of Rehabilitation International; to use its global relations to bring information on new treatments, techniques, and aids to the American rehabilitation community; and to mobilize resources to assist people with disabilities overseas. RIUSA members are offered international forums in specialty areas and a professional international introduction service, as well as notice of international meetings and its many varied publications. A visitor's register and an employment bulletin, both with an international scope, will soon be available. Many rehabilitation agencies work with RIUSA through its Council of Organizations.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : Organization newsletter (Periodically)
Access to the Skies (Periodically)

Name of Organization : **RP Foundation Fighting Blindness**

Address : 1401 Mt. Royal Avenue

Baltimore, MD 21217

Phone No. : (301) 255-9400 (301) 655-1190 (TDD)

(800) 638-2300

Executive Director : Robert Gray

Contact Person : Fran Ludman, Director of Human Services

Chapters/Satellites : 68 local affiliates, including 41 chapters and 27 volunteer information referral centers. The International RP Association is comprised of 18 Sister Foundations

Statement of Purpose :

The RP Foundation supports research into the cause, prevention, and treatment of retinitis pigmentosa (RP) and allied inherited retinal degenerations at centers throughout the United States and England. Its comprehensive program of public awareness and professional education includes regional and national workshops, and distribution of informational materials. Both the National Confidential Registry and the National Eye Donor Program assist statistical and clinical research efforts. Funds are also provided to 12 RP centers.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Fighting Blindness News (Quarterly)

Name of Organization : The Scoliosis Association, Inc.

Address : P.O. Box 194

Manhasset, NY 11030

Phone No. : (516) 627-4030

Executive Director : None

Contact Person : Barbara Schulman

Chapters/Satellites : 40: NY (8); MI; HI; NE; CA (3); IL; AZ; WA; MA; PA (2); IN; FL (3); NC; TX (2); MD; GA; CO; OH; NJ; VA; LA; AL; UT; Canada (3); London, England

Statement of Purpose :

The Association exists to provide support, non-medical information, and insight into the problems of scoliosis to patients, their families and the community. The Association is also dedicated to funding research.

Educational Materials:

Publication(s) : Scoliosis Fact Sheet
Scoliosis, An Annotated Bibliography
Reprints of articles from Backtalk
Index to Backtalk
Outline of Screening Program for Early Detection of Postural Defects of Scoliosis and Other Spinal Deformities

Audiovisual(s) : Scoliosis Screening for Early Detection
Watch that Curve

Newsletter(s) : Backtalk (Quarterly)

Name of Organization : **Sibling Information Network**

Address : Department of Psychology, University of Connecticut
B249 Glenbrook Road, Box U-64
Storrs, CT 06268

Phone No. : (203) 486-4034

Executive Director : Thomas H. Powell

Contact Person : Thomas H. Powell

Chapters/Satellites : None

Statement of Purpose :

The Network was organized to serve as a clearinghouse of information, ideas, projects, literature, and research regarding siblings and other issues related to the needs of families with disabled members. The Network helps its membership through central dissemination of materials and by establishing linkages among members with common interests.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : Society for the Rehabilitation of the Facially Disfigured, Inc. (SFD)

Address : 550 First Avenue
New York, NY 10016

Phone No. : (212) 340-5400

Executive Director : Robert E. Bochat

Contact Person : Robert E. Bochat

Chapters/Satellites : None

Statement of Purpose :

The Society, chartered in New York State in 1951, aids in the rehabilitation of individuals suffering from facial disfigurement. Its major purposes include: (1) to provide facilities for the treatment and assistance of individuals unable to afford private reconstructive surgical care; (2) to assist in the training and education of personnel engaged in reconstructive plastic surgery; (3) to initiate, stimulate, and encourage research in this field; and (4) to carry on a public education program to increase awareness of the problems of facial disfigurement and the treatment methods currently available. The major program of the Society has been sponsorship of the Institute of Reconstructive Plastic Surgery of the New York University Medical Center. The Variety Club Center for Craniofacial Rehabilitation, sponsored by Variety Club of New York, is conducted at the Institute. Also offered to craniofacial patients and their parents is Forward Face, the Institution's support group.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : SFD (Periodically)

Name of Organization : **Spina Bifida Association of America (SBAA)**

Address : 343 South Dearborn Street, Room 317

Chicago, IL 60604

Phone No. : (312) 663-1562

Executive Director : Kent Smith

Contact Person : Joyce Sasso

Chapters/Satellites : 100 chapters nationwide

Statement of Purpose :

The goals of SBAA are to provide information on the fields of medicine, education, and legislation; to provide a list of resources providing financial or other types of support to families and individuals; to help fund research into the causes of spina bifida and the continuing improvement of medical devices and treatment facilities for this birth defect; and to encourage the training of the public and professionals dealing with its care and treatment. It offers an Adoption Information Referral Service, as well as seminars and chapter leadership training.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : Insights (Bimonthly)

Name of Organization : **Support Organization for Trisomy 18/13 (SOFT)**

Address : c/o Kris and Hal Holladay

478 Terrace Lane

Tooele, UT 84074

Phone No. : (801) 882-6635

Executive Director : Kris Holladay

Contact Person : Kris Holladay

Chapters/Satellites : 7 regional groups in the United States plus Canada

Statement of Purpose :

SOFT was established in 1980 to provide support to families of children with trisomy 18 or 13 as well as provide information to the general public about these conditions and birth defects in general.

Educational Materials:

Publication(s) : Trisomy 18: A Book for Families

Audiovisual(s) : None

Newsletter(s) : SOFT (Several issues/year)

Name of Organization : Thrombocytopenia Absent Radius Syndrome Association (TARSA)

Address : 312 Sherwood Drive, RD1
Linwood, NJ 08221

Phone No. : (609) 927-0418

Executive Director : Edward and Sandra Purinton

Contact Person : Edward and Sandra Purinton

Chapters/Satellites : None

Statement of Purpose :

TARSA is a support and education association dedicated to supporting thrombocytopenia absent radius syndrome families. TARSA disseminates information about the syndrome and refers families to one another for the helpful exchange of feelings and shared experiences.

Educational Materials:

Publication(s) : Brochure

Audiovisual(s) : None

Newsletter(s) : (Biannually)

Name of Organization : Tourette Syndrome Association, Inc. (TSA)

Address : 41-02 Bell Boulevard

Bayside, NY 11361

Phone No. : (718) 224-2999

Executive Director : Shirley Friedland

Contact Person : Patricia Breslin, Executive Administrator

Chapters/Satellites : Chapters across the United States of America and internationally: Canada (3), Australia, Great Britain, Denmark, and the Netherlands

Statement of Purpose :

TSA provides programs of public and professional education, family and professional services, and the ongoing support of research. TSA is concerned with such areas as neurological movement disorders, tics, pharmacology, and learning disabilities.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : (Three to four issues/year)

Name of Organization : Turner's Syndrome Society

Administrative Studies Building #006

Address : 4700 Keele Street, York University

Downsview, Ontario, CANADA M3J 1P3

Phone No. : (416) 667-3773

Executive Director : Susan Charney

Contact Person : Susan Charney

Chapters/Satellites : 5: NJ; CA; WA; Vancouver, Montreal, Canada

Statement of Purpose :

The purpose of the Turner's Syndrome Society is to provide services to individuals with Turner syndrome and their families through support groups and public education. It also provides medical information in the hope of reducing the isolation and dispelling the myths surrounding this condition.

Educational Materials:

Publication(s) : The X's & O's of Turner Syndrome

Audiovisual(s) : Turner's Syndrome

Newsletter(s) : (Quarterly)

Name of Organization : United Cerebral Palsy Associations, Inc. (UCPA)

Address : 66 East 34th Street

New York, NY 10016

Phone No. : (212) 481-6300

Executive Director : Leon Sternfeld, M.D., Medical Director

Contact Person : Miriam Holstein, Administrative Secretary

Chapters/Satellites : Approximately 250 state and local voluntary agencies (UCP affiliates)

Statement of Purpose :

UCPA was formed in 1948 to coordinate and assist affiliates. Seven years later the UCP Research and Educational Foundation was established to stimulate and fund research and personnel training. Direct services are provided at the local level, including medical diagnosis, evaluation and treatment; special education; career development; social and recreational programs; parent counseling; adapted housing for the disabled; advocacy; and community education. On the national level, UCPA serves primarily in an advocacy role. The organization carries out extensive research into the causes and prevention of cerebral palsy and also awards fellowships.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : Complete catalogue available upon request

Newsletter(s) : UCPA News (Quarterly)

Name of Organization : United Leukodystrophy Foundation, Inc. (ULF)

Address : 2304 Highland Drive

Sycamore, IL 60178

Phone No. : (815) 895-3211

Executive Director : Ron and Paula Brazeal, Co-Presidents

Contact Person : Paula Brazeal

Chapters/Satellites : None

Statement of Purpose :

The Foundation was incorporated in 1982 to provide emotional support and counseling for families of children with leukodystrophy. Education is provided to members and to the general public through literature and a newsletter.

Educational Materials:

Publication(s) : Facts about Leukodystrophy

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : United Parkinson Foundation (UPF)

Address : 360 West Superior Street

Chicago, IL 60610

Phone No. : (312) 664-2344

Executive Director : Judy Rosner

Contact Person : Judy Rosner

Chapters/Satellites : None

Statement of Purpose :

The United Parkinson Foundation provides a variety of services to its members. Background literature, exercise materials, and regular newsletters are available, as well as access to an extensive referral service. The UPF originated a unique program of educational symposia for patients and their families in 1965, expanding from Chicago to include locations in 18 states and Canada. Six or more such meetings are presently scheduled per year. Funds raised over operating costs provide research grants to established scientists primarily interested in Parkinson disease.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : United Scleroderma Foundation, Inc. (USF)

Address : P.O. Box 350

Watsonville, CA 95077-0350

Phone No. : (408) 728-2202

Executive Director : Sandra H. Stumpf

Contact Person : Diane Williams

Chapters/Satellites : 25 chapters in United States of America and in Canada: AL; AZ; CA (8); FL (2); IL; KY; MI; MN; NJ; NY (2); OH; OK; PA; TN (2); TX; Edmonton, Canada

Statement of Purpose :

USF was established in 1975 with one purpose: to find a cure for scleroderma. Agency goals are: 1) to educate and inform the public about scleroderma and to encourage awareness in the medical profession; 2) to promote medical research by awarding grants to researchers publishing outstanding works in collagen or related diseases; 3) to help patients make and continue necessary contacts with others through chapters, newsletters and workshops; and 4) to accept donations, requests, memorials, and grants on behalf of all of the aforementioned, and to oversee proper and useful distribution of such.

Educational Materials:

Publication(s) : Complete catalogue available upon request

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : Williams Syndrome Association

Address : P.O. Box 178373

San Diego, CA 92117-0910

Phone No. : (619) 275-6628

Executive Director : Gordon Biescar

Contact Person : Gordon Biescar

Chapters/Satellites : 10 regional chapters, covering the United States of America, with a Regional Director assigned to each area

Statement of Purpose :

The National Organization for Parents of Williams Syndrome Children was founded in 1983 for the purpose of uniting affected families to share support and information. Known today as the Williams Syndrome Association, it is still dedicated to this purpose, but will also develop other programs and services for the benefit of its members.

Educational Materials:

Publication(s) : Parent information packet; bibliography of medical journal articles (1800 to present)

Audiovisual(s) : Video tape of NBC "Monitor" segment (1983) describing Williams syndrome

Newsletter(s) : (Quarterly)

Name of Organization : Wilson's Disease Association

Address : P.O. Box 489

Dumfries, VA 22026

Phone No. : (703) 221-5532

Executive Director : Carol A. Terry, President

Contact Person : Carol A. Terry, President

Chapters/Satellites : None

Statement of Purpose :

The Wilson's Disease Association provides aid and support to persons who have Wilson or Menkes disease, and their families. It offers direct financial aid, and an intercommunication network of affected persons for mutual support sharing. The Association also provides current information to those affected, the general public, health care professionals, and other interested parties.

Educational Materials:

Publication(s) : Series of three question-and-answer brochures on Wilson's disease.

Audiovisual(s) : None

Newsletter(s) : (Quarterly)

Name of Organization : Xeroderma Pigmentosum Registry

Address : c/o Department of Pathology, Room C520
Medical Science Building
UMDNJ - NJ Medical School
100 Bergen Street
Newark, NJ 07103

Phone No. : (201) 456-6255

Executive Director : W. Clark Lambert, M.D.

Contact Person : W. Clark Lambert, M.D.

Chapters/Satellites : None

Statement of Purpose :

The Registry was organized to provide a centralized information base concerning xeroderma pigmentosum. Statistical analyses on patient data provide insights into this disease. Professional information is also supplied.

Educational Materials:

Publication(s) : None

Audiovisual(s) : None

Newsletter(s) : None